Southampton

University of Southampton Research Repository

Copyright © and Moral Rights for this thesis and, where applicable, any accompanying data are retained by the author and/or other copyright owners. A copy can be downloaded for personal non-commercial research or study, without prior permission or charge. This thesis and the accompanying data cannot be reproduced or quoted extensively from without first obtaining permission in writing from the copyright holder/s. The content of the thesis and accompanying research data (where applicable) must not be changed in any way or sold commercially in any format or medium without the formal permission of the copyright holder/s.

When referring to this thesis and any accompanying data, full bibliographic details must be given, e.g.

Thesis: Author (Year of Submission) "Full thesis title", University of Southampton, name of the University Faculty or School or Department, PhD Thesis, pagination.

Data: Author (Year) Title. URI [dataset]

University of Southampton

Faculty of Environmental and Life Sciences

School of Psychology

Reviewing and developing on interventions for managing behavioural and mental health difficulties for people with intellectual disabilities.

by

Nicky William Evans

Thesis for the degree of Doctorate in Clinical Psychology

March 2024

0009-0006-0535-6411

University of Southampton

<u>Abstract</u>

Faculty of Environmental and Life Sciences

School of Psychology

Doctorate in Clinical Psychology

Reviewing and developing on interventions for managing behavioural and mental health difficulties for people with intellectual disabilities.

by

Nicky William Evans

It has been reported that people that have a diagnosis of an Intellectual Disability (ID) are more likely to experience anxiety and/or depression at some point throughout their lives; with 10–15% of the population anticipated to present with challenging behaviours. National Institute for Health and Care Excellence recommends practitioners to implement a Cognitive Behavioural (CBT) approach when managing symptoms of anxiety and depression, whilst also considering restrictive practices and physical interventions as a 'last resort' in manage challenging behaviours. Data reporting the management of challenging behaviours is typically reliant on in-patient data. However, more and more people with ID continue to live and access health and social care within community-based services. Moreover, data regarding referrals to Improving Access to Psychological Therapies (IAPT) where CBT is easily accessible, only 1.37% of the total number of referrals comprised of individuals with ID.

Chapter 1 is a systematic review that explore the experiences of staff members, family members and service-users regarding the use of physical interventions in community-based services supporting adults with ID. Six papers were identified and included in an inductive-thematic synthesis. Five key themes were identified, with six sub-themes. Key themes include: staff professional values; negative impact of physical interventions and restrictive practices; service culture; the best interest of staff members, service users, and family members; and the potential of gaining something positive form the implementation of restrictive practices.

Chapter 2 is a novel empirical investigation exploring clinicians' experiences of CBT for people with ID within clinical practice. 15 Clinical Psychologists took part in a semi-structured interview in which four key themes within practitioners' experiences was identified: challenges of working cognitively, making concepts more concrete, practitioners training and preferences, and the challenges and benefits of involving significant others within therapy. Both chapters of this transcript add to the literature by providing insight into lived experiences of the practices applied to managing behavioural and mental health difficulties that people with ID experience.

Keywords: Intellectual Disabilities; Cognitive Behavioural Therapy; Restraint; Restrictive Practice

Table of Contents

Table of Co	ntentsi
Table of Tal	blesv
Table of Fig	uresvii
Research Th	hesis: Declaration of Authorshipix
Acknowled	gementsxi
Definitions	and Abbreviationsxiii
Chapter 1	A thematic synthesis collating the experiences of staff members, family
	members, and individuals with intellectual disabilities on the application of
	restrictive interventions within community-based residences1
1.1 Abst	ract2
1.2 Intro	oduction3
1.3 Met	hod5
1.3.1	Search strategy, search terms and subject headings5
1.	.3.1.1 Intellectual disability5
1.	.3.1.2 Physical intervention5
1.	.3.1.3 Community Settings6
1.	.3.1.4 Subject headings6
1.	.3.1.5 Inclusion and exclusion criteria6
1.3.2	Quality assessment7
1.3.3	Screening, data extraction and analysis8
1.3.4	Reflexivity
1.4 Resu	ılts9
1.4.1	Study characteristics9
1.4.2	Participant characteristics
1.4.3	Synthesis of data14
1.	.4.3.1 Best interest of service user, staff and family14
1.	.4.3.2 To gain something positive from the restrictive practice
1.	.4.3.3 The negative impact of physical interventions and restrictive practice

	-	1.4.3.4 Service culture	
	-	1.4.3.5 Staff professional values	
1.5	Dise	scussion	
	1.5.1	Summary of findings	20
	1.5.2	Strengths and limitations	22
	1.5.3	Implications for research, policy and practice	23
	1.5.4	Conclusion	
Chap	oter 2	Therapeutic practitioners experiences of using Cognitive Behavio	oural
		Therapy with people with an intellectual disability: A thematic ar	1alysis25
2.1	Abs	stract	
2.2	Intr	roduction	27
2.3	Me	ethod	
	2.3.1	Study design	
	2.3.2	Participants	
	2.3.3	Interview schedule	
	2.3.4	Procedure	
	2.3.5	Data analysis	
	2.3.6	Reflexivity	
2.4	Res	sults	
	2.4.1	Challenges of working cognitively with people with ID	
	2.4.2	Making concepts more concrete	
	2.4.3	Practitioner's training and preference	
	2.4.4	Challenges and benefits of Involving significant people within there	ару 37
2.5	Dise	scussion	
	2.5.1	Limitations of study	
	2.5.2	Clinical implication & future research	
	2.5.3	Conclusion	

Appendix A

International Journal of Developmental Disabilities	43

Appendix B

Table of Contents

Doctorate in Clinical Psychology Cover Sheet51
Appendix C
Excerpts from Reflective Journal Log53
Appendix D
Creation of Descriptive and Analytical Themes56
Appendix E
Systematic Review: Coding Manual60
Appendix F
Ethics Approval: Email Screenshot69
Appendix G
Recruitment Advertisement (v3)70
Appendix H
Participant Information Sheet (v4)71
Appendix I
Participant Consent Form (v3)78
Appendix J
Participant Debrief Document (v3)80
Appendix K
Interview Schedule (v3)81
Appendix L
Empirical Project: Coding Manual83
List of References

Table of Contents

Table of Tables

Table 1: Inclusion and exclusion criteria for thematic synthesis	7
Table 2: Characteristics of the studies included in the thematic synthesis	.10
Table 3: Inclusion and exclusion criteria for thematic analysis	.30
Table 4: Participant characteristics	.31

Table of Tables

Table of Figures

Figure 1: PRISMA flow chart of search strategy and study selection	11
Figure 2: Thematic map of themes and subthemes	14
Figure 3: Thematic map of themes and relationships between themes	33

Table of Figures

Research Thesis: Declaration of Authorship

Print name: Nicky Evans

Title of thesis: **Reviewing and developing on interventions for managing behavioural and mental health difficulties for people with intellectual disabilities**.

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

- This work was done wholly or mainly while in candidature for a research degree at this University;
- 2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- 3. Where I have consulted the published work of others, this is always clearly attributed;
- 4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
- 5. I have acknowledged all main sources of help;
- 6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
- 7. None of this work has been published before submission

Signature:Date: 22/03/2024

Research Thesis: Declaration of Authorship

Acknowledgements

Acknowledgements

I would like to thank both of my supervisors, Dr Melanie Hodgkinson and Dr Katy Sivyer. This was my first 'big' project using qualitative research skills and in an area that I am extremely passionate about. You both provided me with expert advice and guidance around this project and supported me through every step; without this, I would not been able to have reached the point of submission.

I would also like to thank my DClin cohort, in particular James Pittman and Jacqui Tiller, who have been a source of motivation and emotion support for me; especially by replying to texts, calls and meet-ups when I have been at my lowest. I would also like to acknowledge my close friends Andrew Hedley that I met when I started my CBT/doctorate journey, and Ben Williams that has been a supporting pillar for me since secondary school. Dr Lawrence Patterson, I would also to thank you for your support and passion within the field of Learning Disabilities/Intellectual Disabilities, which has driven me to continuing doing my best for this population.

Lastly (but not least), I would like to say thank you to both my fiancé Claire and daughter Lexa. I realise the last three years has not been easy, especially with completion of this transcript. Thank you both for the patience and support you have both provided me. The reminders of selfcare, day trips out, lunch at Starbucks, and 'shark attacks' (from Lexa), has gotten me through this, and I can't thank you both enough. Acknowledgements

Definitions and Abbreviations

СВТ	Cognitive Behavioural Therapy. A common psychological treatment
	for a range of mental health conditions, such as anxiety and depression. CBT focuses on four elements: how people think, how
	they behave, their emotions and how their body respond to
	situations. It also incorporated the individuals' beliefs and attitudes.
Challen air a Daharriann	
Challenging Benaviour	Also known in research and publications as 'behaviour that
	challenges' and 'behaviour of concern'. This is not a formal diagnosis
	but defines a number of behaviours presented by a person that can
	cause distress or is a challenge to themselves, the services they
	access, care/support staff, and family members
DSM	Diagnostic and Statistical Manual of Mental Disorders. It is an
	authoritative guide used by health care professionals. It contains
	descriptions, symptoms, and other criteria for diagnosing mental
	disorders. Currently in 2023, the most recent version of the DSM is
	The Diagnostic and Statistical Manual of Mental Disorders, Fifth
	Edition, Text Revision (DSM-5-TR; 2022).
ID	Intellectual Disability. A lifelong neurodevelopmental disorder which
	is typically evident during the individual's developmental period (i.e.,
	childhood). A person with said diagnosis (DSM-V) has deficits in
	intellectual and adaptive functioning which impacts the individual's
	quality of life. The severity of deficits an individual can experience
	ranges from mild, moderate, sever and profound.
NICE	National Institute for Health and Care Excellence. It is an executive
	non-departmental public body of the Department of Health and
	Social Care in England that was set up in 1999. NICE focusses on
	evidence-based research and evaluations, with the aim of publishing
	guidelines on: the use of health technologies within both England and
	Wales National Health Service (NHS); clinical practice for people with
	specific diseases and conditions; public sector workers on health
	promotion and ill-health avoidance; and guidance for social care
	services.

Definitions and Abbreviations

Chapter 1 A thematic synthesis collating the experiences of staff members, family members, and individuals with intellectual disabilities on the application of restrictive interventions within community-based residences

1.1 Abstract

Out of the population of people with an intellectual disability (ID), research reports that 10–15% of these present challenging behaviours (e.g., physical aggression), for which NICE guidelines (2015) recommend restrictive practices and physical interventions as a 'last resort' to manage. The majority of information reported on around management of challenging behaviours is typically reliant on in-patient data. However, more and more people with ID continue to live and access health and social care within community-based services. The aim of this systematic review is to explore the experiences of staff members, family members and service-users regarding the use of restrictive practices in community-based services supporting adults with ID. Six papers were identified and included in an inductive-thematic synthesis: a process of exploring codes, developing descriptive themes and analytical themes. Five key themes were identified, with six sub-themes. Key themes include: staff professional values; negative impact of physical interventions and restrictive practices; service culture; the best interest of staff members, service users, and family members; and the potential of gaining something positive from the implementation of restrictive practices. Results suggest the application of restrictive practices and physical interventions has a number of physical, emotional and psychological impacts on people with ID. Implementing such techniques appear to be driven by ensuring safety for all those likely to be impacted by the behaviours of concern, in addition to the duty that care staff possess within their profession. Furthermore, both care staff and people with ID felt a sense of systemic-rigidity and powerlessness. Future qualitative projects are considered.

Keywords: Intellectual Disabilities; Restraint; Seclusion; Restrictive Practice; Physical Intervention

NB: This thesis has been written for submission and publication with the International Journal of Developmental Disabilities. Guidelines outlined by the International Journal of Developmental Disabilities have been followed and abided to; however, some minor amendments will need to be made prior to submission (e.g., abstract being reduced to 200 words). Please refer to appendix A for journal guidelines.

1.2 Introduction

People that have a diagnosis of an intellectual disability (ID) often experience significant impairment in intellectual functioning, and adaptive and social functioning (American Psychiatric Association, 2013; British Psychological Society, 2015). This is demonstrated with difficulties in problem solving, planning, abstract thinking, academic learning, social interaction, and overall daily living skills (Hronis et al., 2017). Moreover, it has been reported that 10–15% of the ID population often present challenging behaviours (Emerson et al., 2001), such as: physical aggression towards others and themselves, environmental damage, self-neglect and sexually disinhibited behaviours, to name a few (Joyce, 2006). Communication impairments, severity of ID, and living situations have also been reported to be correlated with the presentation of challenging behaviours, such as physical health problems, hospital admissions, application of restrictive practices and negative physical and psychological outcomes affecting the individual's family and support network (Hassiotis & Rudra, 2022; Joyce, 2006; Bowring et al., 2019).

Guidelines provided by the National Institute for Health and Care Excellence (NICE; 2015) recognises the detrimental impact that challenging behaviour(s) can have. Particularly those behaviours which are most frequent and have the most intense and harmful impact on people with ID, and the systems surrounding them. NICE (2015) recommends restrictive practices and the use of restraint and seclusion, as a way of managing such behaviours. NICE notes that physical interventions should be utilised as a 'last resort', which are described as any strategy that ensures a person, or their situation, is safe when challenging behaviours are presented. Strategies can include increasing personal space, withdrawing from grabs and holds, providing as-needed medication, and more restrictive physical and environmental interventions. NICE also identifies that more restrictive interventions may breach a person from entering or exiting certain areas of their environment, seclusion, manual and mechanical restraint, rapid tranquillisation and long-term sedation. Although restrictive practices can be utilised in both community-based settings and in-patient settings, it was historically more frequent within in-patient services where challenging behaviours were reported to be more readily utilised (Borthwick-Duffy, 1994).

Following several investigations around abuse within in-patient services (e.g., British Broadcasting Corporation, BBC, 2011; 2012), a number of departmental reforms and adaptations, such as the Transforming Care Programme (Department of Health and Social Care, 2012) and the creating of the Care Quality Commissionaire (Brown et al., 2019) were developed. The aim of these reforms was to improve health and care services, so individuals with ID and Autism Spectrum Disorder can live in community-settings with the right support. Consequently, it has

3

been reported that there has been a 14-20% reduction of people with ID within in-patient services and that there are approximately 147,915 adults diagnosed with ID that receive local authority social care support; of which 33,140 live in residential care or nursing homes. (Brown et al., 2019). Not only does the presentation of challenging behaviours have a number of negative physical and psychological consequences, but research has identified potential harmful outcomes of the application of restrictive practices. Jones & Kroese (2007) investigated the views of individuals with an ID located at an in-patient service that were restrained frequently. Results suggested that restraint could be a catalyst to potentially abusive situations and that some of the participants felt the staff enjoyed performing restraint and that restraint may or may not serve a purposeful goal.

A systematic review of restrictive interventions was conducted by Heyvaert et al., (2015). Heyvaert and colleagues reviewed 17 papers exploring the experiences of restrictive practices, which included responses from care staff, family members and individuals with ID, in relation to their views, emotions, experiences, acceptability and/or perspectives concerning the use of restrictive interventions. A number of concepts emerged from the dataset, such as people with ID reporting that they often felt sadness, distress, desperation, anger, confusion, and fear, but some also described feeling safe and protected. Whereas staff would often feel anxious, utilising the techniques to preserve the best interest of the patients, and to maintain safety. Moreover, a sense of control also came from the data, in that people with an ID felt that restrictive measures were used unnecessarily, although staff noted that techniques were only used as a last resort.

Though this review by Heyvaert et al. is extremely valuable when considering the impact of restrictive interventions for all those involved, such as staff, family and the individual with ID, it does appear to be biased within the settings the data is collected. Of these 17 papers included in the systematic review, eight papers were based within in-patient specialist services, six were within community settings, two papers were unclear of the settings they were collected in, and one paper was a combination of in-patient and community-based services. In addition to this, of those community-based papers, three of these were collating experiences/perspectives from participants that watched video recordings of restrictive practices being applied; therefore, the datasets recorded for these may not truly reflect the participants' own lived experiences, but more of the opinions they have of the video recordings. The author also did not explore any potential difference between those views and perspectives from community-based settings to that of in-patient services, which makes it more difficult to gain insight into any similarities or differences between the two settings.

As the Transforming Care initiative continues to promote the relocation of individuals with ID from in-patient to community-based services within the United Kingdom, it would be extremely important to gauge the experiences of individuals and their carers (staff or family) around the application of physical interventions, to support and manage times where challenging behaviours are presented. However, the majority of information collected and collated around this is typically from in-patient settings (e.g., Jones & Kroese, 2007) and previous systematic reviews are also fundamentally reliant on in-patient data (e.g., Heyvaert et al., 2015). Thus, the aim of this systematic review is to explore the experiences and opinions of staff members, family members and service-users regarding the use of physical interventions (e.g., restraint) in community-based services supporting adults with ID as a way to potentially assist in the development of future guidelines, protocols, and initiatives that are directed at supporting individuals with ID and the staff teams, along with family members, so that future abuse can be avoided.

1.3 Method

The protocol for this systematic review was registered on PROSPERO (CRD42022374300; www.crd.york.ac.uk/prospero). A Thematic Synthesis approach was adopted as it is a flexible, systematic and transparent method to create and synthesise qualitative data. The method of this approach followed that by Thomas and Harden (2008) and consolidated criteria for reporting qualitative research (COREQ, Tong et al., 2007) was also completed.

1.3.1 Search strategy, search terms and subject headings

Databases utilised in the literature search included Web of Science, MEDLINE, APA PsycINFO and CINAHL PLUS. Search terms also included 'subject headings' of intellectual disabilities and physical intervention.

1.3.1.1 Intellectual disability

In line with The Diagnostic and Statistical Manual of Mental Disorders (DSM-5, American Psychiatric Association, 2013) and that of the guidance on the Assessment and Diagnosis of Intellectual Disabilities in Adulthood by the British Psychology Society (BPS, 2015), we considered a diagnosis of an intellectual disability to include the individuals to have an IQ lower than 70; significant impairment of adaptive functioning, and present before the age of 18 years. Key words therefore: 'intellectual disabilities', 'intellectual disability', 'learning disabilities', and 'learning disability'.

1.3.1.2 Physical intervention

The focus of this Qualitative Review would include experiences of the use of physical interventions. NICE (2015) guidelines and definitions of physical interventions were considered

and key words included for this domain were: Physical Intervention, Seclusion, Restrain(t), Restrictive Practice(s), Conflict Management, Physical restrain(t), Mechanical Restrain(t). As and when needed medication (p.r.n) was not included as a search term, and papers that were targeted at the use of medical or chemical restraint or intervention were excluded. In accordance with NICE guidelines, medication can be provided as a proactive treatment, for example antipsychotics and sedatives may be used for mental health conditions such as psychosis and anxiety (NICE, 2015). However, it may not be clear in the literature if these medications were used solely as a restrictive intervention, as a proactive intervention, or as a combined approach to managing challenging behaviours and/or mental health conditions.

1.3.1.3 Community Settings

As this review was aimed at exploring the experiences of those within a community/residential setting, it was imperative to target papers that included individuals based at these locations. These included: residential housing, educational-residential settings, supported living services, day-services for individuals with Intellectual Disabilities and living with family members/carers. Key words relating to community settings were not included as a search term as there are situations within the literature that services are described rather than labelled; therefore, to ensure potential papers were not excluded prior to text-screening, we refrained from including this term as a search term but was included in our inclusion and exclusion criteria.

1.3.1.4 Subject headings

Major and minor subject headings were also combined with our search terms to ensure we were able to draw on papers that may be potentially missed. These terms included: Intellectual Disability, Intellectual Disabilities, Learning Disability, Learning Disabilities and Physical Restraint.

1.3.1.5 Inclusion and exclusion criteria

A number of inclusion and exclusion criteria were used, as shown in Table 1 below.

Table 1: Inclusion and exclusion criteria for thematic synthesis

Inclusion Criteria	Exclusion Criteria		
Physical intervention used with adults with a diagnosis of an	Quantitative studies that are primarily reviewing the		
Intellectual Disability (18 years old - end of life).	effectiveness of an intervention.		
Living in Community/residential	Single Case Studies.		
settings.	Population where children or		
Experiences from staff/family/individual with ID.	adolescents under the age of 18 years old were involved.		
Qualitative surveys or feedback from quantitative research.	Where papers were not in relation to physical interventions.		
Qualitative elements of Quantitative Research.	Were based on a population that resided in in-patient services or were a case study.		
No restrictions on the publication date, but all studies had to be written in English.	Where chemical/medical intervention were used.		
	The population were not diagnosed with an ID.		
	Where the data collected was only quantitative data.		
	Reviews, books/chapters, and conference extracts were excluded.		

Note: for the purposes of this thesis submission, Table 1 has been included in the full write up. For the purposes of journal publication, it will be removed and added to the appendices as in line with the journal requirements.

1.3.2 Quality assessment

The Critical Appraisal Skills Programme: Qualitative Studies Checklist (CASP, 2022) tool was used to examine the validity, results and relevance of findings of each of the studies chosen for the final analysis to confirm the paper(s) included were appropriate and robust.

1.3.3 Screening, data extraction and analysis

Initially the primary researcher identified papers by implementing the search strategy, applying inclusion and exclusion criteria, and then reviewing the abstracts of remaining papers (April 2023) utilising RAYYAN (Ouzzani et al., 2016) to organise and review the papers. A second reviewer was introduced, that being a trainee clinical psychologist, to support with ensuring the finalised papers were appropriate for this systematic review. Due to the timing and nature of this systematic review, guidelines around rapid reviews were followed in that the second reviewer dual screened 20% of abstracts, with discussions around any variance (Moons et al., 2020; Garritty et al., 2021). The introduction of the second reviewer was during the title and abstract screening stage, as research by Stoll et al., (2019) noted that a second reviewer at this stage could identify between 6.6% - 9.1% more eligible papers. Due to time restraints, we were unable to repeat this reviewing method for full-text eligibility, though this approach has been considered to be a methodological shortcut in rapid reviews (Waffenschmidt et al., 2019). A total of 104 titles and abstracts were reviewed by the second reviewer with no discrepancies. Final papers were presented and discussed with the research team.

Data extraction was completed by the primary researcher in line with Thomas & Harden's (2008) recommendations which involved line by line coding of all data, including author interpretation of raw data and results in both the result and discussion sections of the six papers identified. The codes were then used in the development of descriptive themes and finally development of analytical themes, which is demonstrated in appendix C. Third order interpretation of the data included the original data, author interpretation and creation of analytical themes of this synthesis, as suggested by Thomas & Harden (2008) and that of Barnett-Page & Thomas (2009). Initial Thematic Mapping was completed by the primary researcher, using NVivo 13 (QSR International Pty Ltd., 2020), and discussed with the research team, resulting in a finalised coding manual being created (appendix D). The papers included in this project involved the experiences of people with ID, care staff, family members, and author interpretation. Initially, each of these groups of participants were analysed separately, although the themes and subthemes across the project encompasses the experiences of these groups as a whole.

1.3.4 Reflexivity

The research team consisted of the primary researcher, (a third year Trainee Clinical Psychologist completing this project as part of their Doctorate in Clinical Psychology thesis), a qualified and chartered Clinical Psychologist, and a Research Psychologist. Help was also provided by a further a third year Trainee Clinical Psychologist from the course to assist with reviewing 20%

of papers. The epistemological approach for this investigation is that of a critical realist. Two members of the research team had clinical and research experience with an ID population, with one member having lived experience of supporting an individual with ID. One member of the team did not have any clinical, research or personal experience of working with people with ID.

The research team met regularly to discuss the project and reflect on each stage of the thematic synthesis. Throughout the analysis process, the primary researcher managed ongoing notes and a reflective log as a process of refection regarding data analysis and team supervision.

1.4 Results

A total of six papers met our inclusion criteria of the original 1267 identified by our search strategy (see **Figure 1**). The characteristics of the studies included in the thematic synthesis are outlined in **Table 2**, including the CASP quality assessment rating.

1.4.1 Study characteristics

Of the six papers included, five reported perspectives from staff members within their project (Mérineau-Côté & Morin, 2014; Hawkins et al., 2005; Björne et al., 2022, Van der Meulen et al., 2018; Ravoux et al., 2012). Two of these papers also included the perspectives of people with an ID as an addition (Mérineau-Côté & Morin, 2014; Hawkins et al., 2005). Only one paper reviewed the experiences and perspectives of family members (Elford, et al., 2010).

Five of the papers implemented a semi-structured interview, and only one of the papers (Björne et al., 2022) used a survey in which respondents would provide answers via a Likert scale and free-text section. Of the two papers that included interviews with people with ID (Mérineau-Côté & Morin, 2014; Hawkins et al., 2005), the semi structured interview was an adapted interview for those people with ID, which paid specific attention on the wording of the questions, did not use double negatives and had response choices prepared prior to the interview taking place in case the participant did not know how to respond. The adapted interview schedule was initially created by Hawkins et al., (2005) and then utilised within the research conducted by Mérineau-Côté & Morin (2014). The survey utilised by Björne and colleagues (2022) consisted of five questions in relation to the application of restrictive practices, which required the respondents to answer via a likert scale but also included a free-text box. We did not include the likert scales within this thematic synthesis.

1.4.2 Participant characteristics

Two of the papers did not identify the age ranges of their participants (Björne et al., 2022; Van der Meulen et al., 2018), with a total of five papers noting that all participants were 18 years or older. Of the four papers reporting participant ages in detail, these ranged from 18 – 78 years old, which included a total of nine men and seven women that had a diagnosis of ID. One man and seven women were noted to be family members, and there were 292 staff members, of which 218 were women, 67 men, with seven being identified as 'Non-disclosure/other'. Figure 1: PRISMA flow chart of search strategy and study selection (Page et al., 2021).

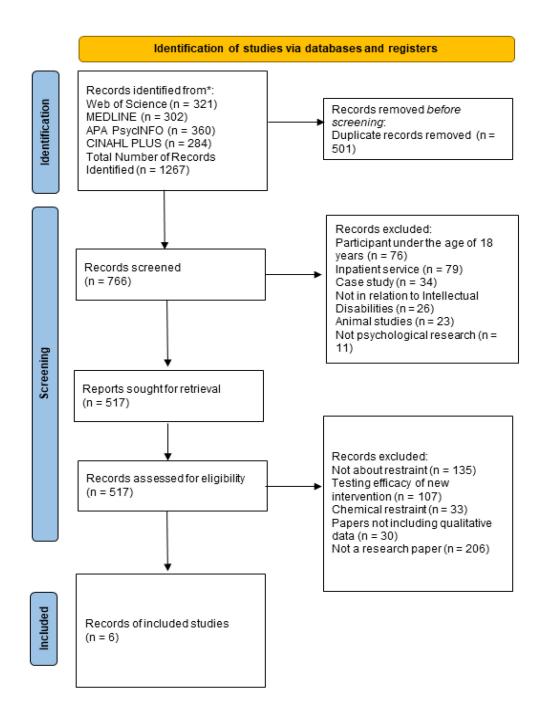


Table 2: Characteristics of the studies included in the thematic synthesis

Source	Study aim(s) relevant to this analysis	Sample Size & Demographics	Methodology	Settings (Country)	CASP Quality rating (out of 10)
Björne, Deveau, McGill & Nylander (2022)	Identify what promotes/hinders organisational change. What restrictive measures do staff report using and the important of reducing these. What organizational changes do staff identify to contribute to the reduction of restrictive measures.	n = 250 care staff M = 54 F = 189 Not other demographics presented.	Survey of five questions (Likert scale) which also included a free text box for the participants to add additional notes and perspectives.	Sweden	6
Van der Meulen, Hermsen &	Examine restraints used and the	n = 15 care staff	Semi structured	Netherlands	7
Embregts (2018)	way support staff justified this use.	M = 2	interview		
		F = 13			

Not other demographics

presented.

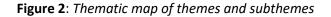
Source	Study aim(s) relevant to this	Sample Size & Demographics	Methodology	Settings (Country)	CASP Quality rating
	analysis				
					(out of 10)
Ravoux, Baker & Brown (2012)	Explore staff members' perspectives	n = 11 care staff	Semi structured	England,	7
	of managing clients with challenging	Gender not identified.	interview	United	
	behaviours in residential services.	Ages = 20-46 years		Kingdom	
Elford, Beail & Clarke (2010)	Explore parents' experiences of	n = 7 family members	Semi structured	England,	7.5
	using restraint with their adult	M = 1	interview	United	
	son/daughter with ID.	F = 6		Kingdom	
		Age = 47-78 years			
Mérineau-Côté & Morin (2014)	How individuals with ID and support	N = 8 people with ID & 8	Semi structured	Canada	8
	staff perceive the use of restrictive	care staff	interview		
	measures, the reasons for their use,				
	and their perceived effect on those	staff demographics			
	involved.	M = 0			
		F = 8			

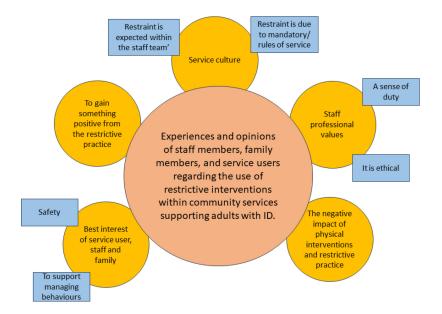
Source		Sample Size &	Methodology	Settings	CASP Quality
		Demographics		(Country)	rating
					(out of 10)
		Not other demographics			
		presented.			
		ID demographics			
		M = 3			
		F = 5			
		Age = 20-50 years			
Hawkins, Allen & Jenkins (2005)	Explore the personal impact of	N = 8 staff & 8 person	Semi structured	Wales,	8
	receiving and implementing physical	with ID	interview	United	
	interventions, and how people with			Kingdom	
	ID and staff felt the use of such	staff demographics			
	procedures impacted those	M = 5			
	involved.	F = 3			
		Age = 26-53 years			

Source	Study aim(s) relevant to this analysis	Sample Size & Demographics	Methodology	Settings (Country)	CASP Quality rating (out of 10)
		ID demographics			
		M = 6			
		F = 2			
		Age = 18-43 years			

1.4.3 Synthesis of data

Based on our Thematic Synthesis of the data, five key themes and six subthemes were identified, as seen in **Figure 2** below.





1.4.3.1 Best interest of service user, staff and family

Throughout the papers there was a general consensus that the use of restrictive practice and physical interventions were perceived to be in the best interest of the service user, other service users, family members and staff. Best interest has two key interconnected dimensions, namely: safety and managing challenging behaviours.

Safety included the safety of the individual presenting with the challenging behaviour and other people. Staff appeared to be aware of potential risk(s) the challenging behaviour could cause towards the individual themselves, staff members, other service users, and family members:

"They were safer after the measure had been used." (Mérineau-Côté & Morin, 2014: staff).

"oh no...we've got to think of your..you know, your safety...I know how to deal with her, I've been dealing with her for years." (Elford, et al., 2010: staff). However, the service user presenting with the behaviour also appeared to be aware of the risk and potential negative outcome towards others, and not focus so much on the risk they pose towards themselves:

"So they're safe from me. That's why they hold me. I might hurt them." (Hawkins et al., 2005: person with ID).

Whereas family members were more conscious of the risk towards themselves whilst implementing a physical intervention, in addition to worrying about the potential risk others face whilst using said techniques:

"My husband doesn't particularly like me doing it because he always says I'm putting myself in danger and that and I said well, what else can I do when I'm on my own and he's going for me." (Elford, et al., 2010: Parent).

There was also some emphasis on feeling uncomfortable implementing the techniques, as quoted by author:

"Most staff members stated that they did not enjoy using restrictive measures...sometimes necessary, as a last resort, to ensure the safety of all parties." (Mérineau-Côté & Morin, 2014: author).

As a way to ensure safety was achieved, authors interpretation and staff spoke about taking control of the situation as they felt the individual with ID could not control what they were doing. Consequently, by taking control it was felt that this reduces the potential negative consequence(s) of the behaviour escalating further and thus avoiding any further negative outcomes, which was also reported to be echoed by family members:

"Restrain her son for both his [person with ID] sake and hers [parent] to avoid the situation getting out of control." (Elford, et al., 2010: author).

"[Author]: Another said she felt reassured because of the reduced risk of aggression during seclusion. [staff]: 'of course it's more reassuring because there aren't any risks of aggression'." (Mérineau-Côté & Morin, 2014: author and staff).

Authors also reported that staff felt that the recipient of the intervention had an element of choice with how the challenging behaviour was best managed, again highlighting the perceived importance of control with the application of restrictive measures from the staff:

"Or they offer clients a choice between various restraints of freedom." (Van der Meulen et al., 2018: author).

"Used at this person's request, such as when he felt unstable and needed additional support." (Mérineau-Côté & Morin, 2014: author).

It was also noted that staff perceived having confidence in managing situations was important to them when trying to maintain safety and best interest of both the staff team and the person presenting with challenging behaviours:

> "it is really about giving the staff team the skills to be able to respond to a number of situations within the home environment and within the public in the community, to be able to sort of make them feel confident to be able to respond to different things." (Ravoux et al., 2012: staff).

"supporting people with challenging behaviour on ensuring staff were prepared to manage high risk behaviours in the safest way. This process aimed to make a relatively unpredictable phenomenon more predictable and equip staff with the necessary resources to be able to do so appropriately (Ravoux et al., 2012: author).

1.4.3.2 To gain something positive from the restrictive practice

The perception of staff members, authors, and the individual with ID identified that it is possible the recipient of the physical intervention may gain something positive from the intervention. Staff reported to feel that those individuals presenting with behaviours of concern gain reinforcements such as engaging in potential favoured activities (e.g., interaction from others), or gaining a sense of control, safety, and comfort. In addition, service users reported a sense of comfort from physical intervention. Moreover, it was said that the intervention enabled communication between the staff and service user (e.g., expressing their emotions such as anxiety), and also settling their bodily reactions to difficult emotions such as tense muscles; thus gaining a sense of security:

"For one staff member, the use of a restrictive measure also had positive consequences such as an increased frequency of contacts with the user." (Mérineau-Côté & Morin, 2014: author).

"She [person with ID] relaxes into you [staff] holding her like that...She wants you to be holding her." (Hawkins et al., 2005: staff)

"Comment made by a service user was related to comfort and came from service user 1. In response to the question 'How does your body feel?', she replied 'comfortable'. (Hawkins et al., 2005: author and person with ID).

1.4.3.3 The negative impact of physical interventions and restrictive practice

Though people with ID and staff have noted some potential benefits from the application of restrictive interventions, there does seem to be a number of comments made regarding negative impacts of said interventions in a physical, psychological and emotional way. The positive impacts seem to be more psychological in nature such as gaining relief or comfort, however the physical outcome of applying the intervention(s) to the individual is physically demanding for both staff and the person with ID. Furthermore, the recipient(s) of the intervention noted pain as a primary consequence:

"[Interviewer] How did that used to make you feel? [Service user] Sad. [Interviewer] How did your body feel when you were on the floor? [Service user] It hurt on the floor". (Hawkins et al., 2005: person with ID).

"However, this is uncomfortable for him. He doesn't think it is necessary." (Van der Meulen et al., 2018: staff).

"He'd woken up in the night at some time and he got his arms stuck in the bed guard and ended up with some nasty bruises, so that was a result of doing that, so we choose not to use bed guards now". (Elford, et al., 2010: Parent).

Psychologically, the impact of the intervention(s) was noted to affect the relationship between the service user and the member of staff applying the intervention; particularly due to the recipient not liking the intervention and feeling helpless:

"It can cause stress and a sense of abuse for the service user, which has a negative psychological impact on those affected." (Björne et al., 2022: author)

"Managing the clients' behaviour had an impact on the quality of their rapport with clients." (Ravoux et al., 2012: author).

Additionally, there were opposing views of why the intervention was needed, such as: staff feeling fed up of the service user, or that staff were applying the intervention due to wanting to punish the service user. Consequently, this may have ruptured the relationship between the individual with ID and staff members:

"[author] During the Physical Intervention relates strongly to their beliefs about, and experiences of, service user behaviour. Service user: Probably fed up...fed up with me." (Hawkins et al., 2005: Person with ID). "staff members felt that some users perceived the restrictive measure as a form of punishment: 'I think she sees it more as a punishment'." (Mérineau-Côté & Morin, 2014: author & staff).

Regarding the emotional impact restrictive measures and physical intervention provided, there may be some distress experienced during the intervention as staff noted feeling relief following the ending of a restraint procedure:

"Interviewer: After, when it is over, are you happy or sad? User: 'Happy', 'I am happy to get out [of the room]". (Mérineau-Côté & Morin, 2014: author & staff)

"staff described feeling the Physical and Emotional Aftermath of the intervention, once the walking on Eggshells period had passed, which was accompanied by an enormous sense of relief that it was all over". (Hawkins et al., 2005: author)

Yet, ultimately there appeared to be mainly a negative emotional experience for the person with ID. There also seems to be a sense of the staff members being rude towards them and impact on their self-esteem:

"I feel silly and daft...because of what I've done. I feel like it shouldn't have happened. Like I've let myself down." (Hawkins et al., 2005: person with ID)

"Not very happy...because I was restrained and rude again." (Hawkins et al., 2005: person with ID).

"Experiencing irritation, anger, fear, and to a lesser degree, disgust, guilt, sadness, helplessness and shock." (Ravoux et al., 2012: author).

1.4.3.4 Service culture

A powerful systemic theme developed throughout the analysis of the data, particularly around how staff felt the culture of the staff team, the way in which the team operates and interacts with each other, and the rules of the team and organisation. It appeared that systemic legislation and how it directed organisations were important when considering why staff applied restrictive practices and physical interventions to managing challenging behaviour:

> "Some staff mentioned that they only applied restrictive measures that were mandatory under forensic or compulsory psychiatric care legislation." (Björne et al., 2022: author).

"Excuse me, but what century are we talking about, unless it is a forensic ward.". (Björne et al., 2022: staff).

It further appeared that how the organisation operated and was managed also shaped how staff members functioned within their role, which at times seemed to be limited where they may have felt a sense of powerlessness and frustration. Consequently, resulting in restrictive practices and physical interventions being applied:

> "We are here to help them; we are here to work alongside them in their lives...I am a manager; I will tell you that these are the rules. I tell the staff these are the rules." (Ravoux et al., 2012: staff).

> "She screams and shouts because she wants to get out of her bed. But we start at 7.30 A.M., so she has to adjust herself to the organisation. The organisation doesn't adjust to her." (Van der Meulen et al., 2018: staff).

The authors' conclusion from a number of the papers was that they felt that staff would perceive the use of restrictive practices as typical process and it was an expectation in managing difficult situations. Consequently, this culture within the team may have de-sensitised the staff to the application of restrictive practices, which in turn made said practices happen more frequently and thus was a justification for restrictive practices and physical interventions, which potentially was an inappropriate response from the team.:

> "There was a concern that where restraint is part of the culture of services then it will end up being used." (Elford, et al., 2010: author).

> *"When staff use a measure frequently, then it is not perceived as restrictive." (Björne et al., 2022: author).*

"Physical interventions just 'happen' to him." (Hawkins et al., 2005: author).

1.4.3.5 Staff professional values

The final theme we developed from reviewing the papers is that of professional values, predominantly in relation to the staff supporting the individuals with ID. The professional values the staff held primarily around their sense of duty for their role as a healthcare professional, and the ethical dilemma they felt using restrictive practice and physical interventions.

The sense of duty the staff felt within their job appeared to relate to their role to deescalate situations where challenging behaviours were presented:

Chapter 1

"I might sound awful, we've actually put Tom in his bedroom... basically took everything out and put Tom in his bedroom with a brush...to stop him from coming out...for his own safety and our safety". (Elford, et al., 2010: Parent).

"If it can be avoided in any way, whatsoever then that's our job, because the service user loses twice, don't they?" (Ravoux et al., 2012: staff).

Moreover, sense of duty also presented itself in how the staff conduct themselves within their role:

"When you come to work you leave everything on the doorstep, you are a role model here". (Ravoux et al., 2012: staff)

"I can't walk away, this is my job." (Hawkins et al., 2005: staff).

There also appeared to be a number of ethical issues that arose for the staff relating to the use of restrictive practice and physical interventions. Ethical issues that were apparent were the vulnerability of the service users, the use of restraint as a last resort, perceived power, and the potential misuse of restrictive practice and physical interventions:

"It was recognised that there are clear limits to restraint and that it needs to be used carefully." (Elford, et al., 2010: author).

"So there are times when it's necessary if a person isn't aware of what can happen. You know, if someone's gonna put their hand in the fire you wouldn't just watch and not do anything". (Elford, et al., 2010: Parent).

"The power in restraint, and potential for misuse of this was highlighted." (Elford, et al., 2010: author).

"Actually, allowing a relationship [romantic relationship] to happen is the worst thing to do... Clients change their behaviour, aggressive behaviour increases or behaviour that is difficult to interpret appears. Emotions. A lot of things come out in an explosion". (Van der Meulen et al., 2018: staff).

1.5 Discussion

1.5.1 Summary of findings

Through the thematic synthesis, a number of themes were identified when exploring the experiences of staff members, family members, and individuals with ID relating to the application

of restrictive interventions within community-based facilities and residences. Firstly, there seemed to be an overall accordance from all those studies and participants that restrictive practices are in place for the best interests of the people with an ID, and as a way to protect the individuals from harming themselves, harming other people and becoming harmed from others. Heyvaert and colleagues (2015) conducted a systematic review of inpatient services where they also found that staff perceived restrictive practices as a way to preserve the best-interest of the patients, and safety. With this said, this thematic synthesis also found that staff felt it was their duty as a healthcare professional to ensure they maintain the persons safety and that at times it was more ethical to apply the restrictive practice, than not.

This is an important theme to further understand, as a considerable number of individuals with ID present with behaviours of concern that can cause injury to themselves and others (Emerson et al., 2001). Whilst historically individuals with such behaviours have been placed within in-patient services, due to legislations with the UK promoting community-based support (e.g., Transforming Care Programme, Department of Health and Social Care, 2012), it means that they may be having contact with professionals with a reduced level of academic and clinical experience. Research has reported that traditionally two-thirds of all available mental health nurses were employed in psychiatric hospitals (Lora et al., 2020) and that the overall qualified nursing levels have reduced between 2011 and 2021 (Brimblecombe, 2023). For example, a qualified nurse in the UK is required to do a minimum of thee-years academic training at university, whilst non-qualified care staff are measured by 'on-the-job training' through vocational qualifications which can span over 18-months, such as National Vocational Qualification (NVQ) and Qualifications and Credit Framework (QCF). This, therefore, could impact the way in which people respond to challenging behaviour(s) and perceive safety and their professional duty.

The culture and daily operations of the service were also said to be influencers of applying restrictive practices, potentially resulting in them being used inappropriately. This was also reported by Jones & Kroese (2007) during their qualitative project, investigating the views of people with ID in inpatient facilities who are restrained frequently. They found that restraint could be a catalyst to potentially abusive situations and that some of the participants felt the staff enjoyed performing restraint and that restraint may or may not serve a purposeful goal. It seems that restrictive practices can be positively reinforcing for the individual with ID, such as gaining the attention and comfort of others, in addition to gaining a sense of control over their environment. However, there was a general consensus that there are a number of physical, psychological and emotional consequences, predominantly negative, due to the impact of physical interventions and restrictive practice. The latter of which has again been found in inpatient investigations such as Bower et al., (2003) and Heyvaert et al., (2015) where individuals

21

Chapter 1

with ID experienced sadness, distress, desperation, anger, confusion, and fear, but also described feeling safe and protected. Moreover, a qualitative paper by Wolkorte et al., (2019) found that people with ID that also presented with challenging behaviours preferred less restrictive approaches when managing challenging behaviours, such as more detailed assessments of the person's behaviours, non-pharmacological interventions and reviewing health professionals' approach. This therefore is a possible reflection of how a staff team may culturally approach individuals with ID and the importance of a collaborative approach to managing challenging behaviours.

1.5.2 Strengths and limitations

This thematic synthesis highlights and adds to the limited research papers exploring the experiences of staff members, family members, and individuals with ID relating to the application of restrictive interventions within community-based facilities and residences.

As previously mentioned, since the introduction of the Transforming Care Program (Department of Health and Social Care, 2012) and other reforms and programs that have followed this, there has been an overall reduction of people with ID within inpatient services (Brown et al., 2019), and it is forecasted that there will be a continuation of moving people out of inpatient services; yet the majority of research around restrictive practices have been conducted within inpatient services. Therefore, this thematic synthesis promotes further exploration into community-based services that people with ID are accessing. Although there seems to be some commonality between community and inpatient research (e.g., negative psychological, physical and emotional impact of restrictive practices), there may be some aspects that are specific to community-based facilities, such as the positive benefits that the individuals with ID gain (i.e., interaction and comfort), in addition to the involvement and experiences of family members.

Regarding the quality rating, it appears that the papers that were analysed for this thematic synthesis were appropriate from their scores on the CASP tool. The papers had mostly clear statement of aims of their research, appropriate research design and methodology. However, with this said, this thematic synthesis does have its limitations. Firstly, the total number of papers that were included in this report is limited, as only six papers were identified. This would therefore limit the overall 'pool' of experiences on this topic. Furthermore, only one of the six papers referred to the ethnicity of the participants that attended the studies (Ravoux et al., 2012) and of all the participants demographics included, men only represented 23% with 77% being female of the participant pool. This, therefore, poses a larger issue with generalisability of this project as it seems they lack consideration for equality and diversity within their subject pool.

1.5.3 Implications for research, policy and practice

Following the conclusion of this project, it is felt that further research is needed regarding restrictive practices and measures implemented within community-based services for individuals that have ID. Such areas that would benefit from this include staff experiences of support around reducing restrictive practices and debriefing following incidents of challenging behaviours. Moreover, there is very limited research into family members experience of having a loved one access community-based services where restrictive practices are utilised. This would be key to further supporting people with ID, as family members, particularly those that have cared for individuals with ID for many years, may have more idiosyncratic proactive and reactive techniques to de-escalate situations other than restrictive practices and physical interventions. It is reassuring that there was an agreement on the best interest of the individual with ID, although future research and developments around how staff are trained to ensure this is done in a positively effective way would be key in avoiding potential misuse of restrictive practices. It is possible that by keeping in line with the "best interest" for service users, it may lead to misuse of restraint. It may be that to act in an individual's best interest is to apply restrictions and restrain them from engaging in what may be perceived as an unwise decision or act. As concluded by Cave (2017), practitioners may make assessments of mental incapacity that are not truly justified. Consequently, resulting in the misuse of powers by health professionals when applying restrictive approaches even when the intent behind these could be for the individual's best interest and wellbeing. This could create a culture where restraint and restrictive practices are expected or normalised. Research could therefore be exploring the training programs support staff undergo within their role, combined with the perceived culture they are situated within, and frequency of proactive interventions rather than restrictive practices and physical interventions. It would be important for those staff and family members supporting individuals with ID to follow guidance provided by the British Psychological Society on models and frameworks for reducing restrictive practices (Shaw, Thomas & Hardiman 2022), in addition to supporting individuals with ID in their awareness and understanding of this guidance regarding their care.

1.5.4 Conclusion

The application of restrictive practices and physical interventions has a number of physical, emotional and psychological impacts on people with ID. As a result of challenging behaviours escalating, care staff, family members and people with ID have noted to feel anxious and fearful, with the risk of physical injuries due to the challenging behaviours directly, or the restrictive practices and physical interventions being implemented. However, the intent behind implementing such techniques appears to be driven by ensuring safety for all those likely to be

Chapter 1

impacted by the behaviours of concern. Care staff also feel that they have a duty as healthcare workers, and if a restrictive approach is deemed to have lesser negative impact (psychologically and physically), then it is their duty to implement these approaches. Both care staff and people with ID felt a sense of systemic-rigidity and powerlessness, in that care staff have to do what they are told, and individuals with ID have interventions done to them, often without fully understanding why. Although the papers included in this project are small, they reiterate some previously identified concepts for people with ID and the use of restrictive practices and physical interventions (e.g., potential for abuse). Moreover, this thematic synthesis also highlights new concepts identified within community-based settings, such as the beliefs care staff hold around professional values and potential receipt of something positive that people with ID may gain from restrictive practices and physical interventions. Limitations are considered, particularly around equality and diversity of the papers, and a number of future projects around further exploration of family members experience of restrictive practices and physical interventions are outlined.

Chapter 2Therapeutic practitioners experiences of using
Cognitive Behavioural Therapy with people
with an intellectual disability: A thematic
analysis

2.1 Abstract

IAPT data (2022) suggests 1.81 million people accessed the service over a 12 month period, with only 1.37% of the total number of referrals comprised of individuals with Intellectual Disabilities (ID), even though anxiety and depression have been found to be more prevalent for this population. Treatment for anxiety and depression for individuals with ID follows typical NICE guidelines, primarily using Cognitive Behavioural Therapy (CBT) though it has been suggested some practitioners are hesitant to use it. Research has touched upon some elements of CBT that are helpful for this population, though concluding more research is needed in better understanding the components of CBT. The current qualitative project aims to explore clinicians' experiences of CBT for people with ID within clinical practice. 15 Clinical Psychologists working within the field of ID were recruited to attend a semi-structured interview to explore their experiences of using a CBT approach for this population. Results indicate four key themes within practitioners' experiences: challenges of working cognitively, making concepts more concrete, practitioner's training and preferences, and the challenges and benefits of involving significant others within therapy. Key themes are discussed in depth and future work, such as research into diagnostic overshadowing, eligibility to accessing CBT at a primary care level, and people with ID's views of accessing CBT, are explored.

Keywords: Intellectual Disabilities; Cognitive Behavioural Therapy; Therapeutic Practitioners; Anxiety; Depression

NB: This thesis has been written for submission and publication with the International Journal of Developmental Disabilities. Guidelines outlined by the International Journal of Developmental Disabilities have been followed and abided to; however, some minor amendments will need to be made prior to submission (e.g., abstract being reduced to 200 words). Please refer to appendix A for journal guidelines.

2.2 Introduction

The prevalence of Intellectual Disability (ID) in the UK is said to be 2.16% (Public Health England, 2016; Office for National Statistics, 2021). Of this, anxiety and depression are said to effect 27-50% and 13-17% of the population respectively (Groves et al., 2022; Scheirs et al., 2023; Hermans et al., 2013); though researchers suggest that the prevalence of anxiety and depression is underdiagnosed (Maïano et al., 2018). People with ID are also more likely than the general population to experience additional comorbidities such as schizophrenia and phobias (Deb et al., 2001); in addition to adverse life events such as bereavement, moving home, sexual abuse, and chronic diseases. These adverse experiences have been noted to contribute to the increased prospect of experiencing anxiety and depression (Brown et al., 1993); in addition to the stigma of having an ID diagnosis (Hermans & Evenhuis, 2012; Hulbert-Williams & Hastings, 2008; Hermans & Evenhuis, 2013; Ali et al., 2015).

Guidelines provided by the National Institute for Health and Care Excellence (NICE) indicate that professionals should offer Cognitive Behavioural Therapy (CBT) for a variety of common mental health conditions, such as anxiety disorders, depression and trauma (NICE, 2011, 2018, 2022). Research highlights the effectiveness of CBT for common mental health conditions, such as anxiety and depression not only short-term but also up to three-five years following treatment (Wiles, 2016). CBT has also been shown to be effective when working with more complex disorders such as psychosis (Hutton & Taylor, 2014), and eating disorders (Cooper & Shafran, 2008). Within England, the most cost effective and efficient way to access CBT treatment is through Improving Access to Psychological Treatment (IAPT) services, at a primary care level. Whilst CBT can also be offered through more specialist services for severe and enduring disorders. Data from 2021 – 2022 reports that 1.81 million people accessed IAPT over a 12-month period in which 91.1% started treatment within six-weeks and 50.2% moved to recovery following completion of treatment (NHS Digital, 2022). However, research exploring IAPT data from 2013 – 2020 found that individuals with ID represent just 1.37% of the total number of referrals to IAPT service (Dagnan et al, 2022), which could be an underrepresentation of the amount of people with ID an anxiety and depressive disorder.

Regardless of how a person with ID accesses CBT treatment, NICE (2016) recommends practitioners follow a typical treatment plan in line with specific mental health conditions for the general population (e.g., Generalised Anxiety Disorder), whilst considering adaptations to therapy. Such considerations and adaptations may include communication needs, decision-making capacity, the degree of learning disabilities, and treatment setting. However, NICE reported that therapists are reluctant to implement a CBT approach for this population. Such a reluctance may

27

be due to the initial argument that people with ID are unable to engage in cognitive-based psychological therapies due to their cognitive deficits (Adams & Boyd 2010; Butz et al. 2000), which inevitably means people with ID may be unable to access a readily available evidence-based psychological treatment. Research directed specifically at individuals with ID and the effectiveness of CBT treatment suggest that CBT has long-term superiority in treating symptoms consistent with anxiety and mood related disorders (McGillivray & Kershaw, 2015; Roberts & Kwan 2018). People with an ID have also reported positive experiences of CBT treatment in relation to alleviating distressing symptoms (Pert et al., 2013). However, a number of authors have concluded that more research is needed, to understand the effective CBT components that sustain positive changes, such as the use of cognitive interventions in CBT (Bekirogullari, 2018; Jennings & Hewitt, 2015; Unwin, 2016; Taylor et al., 2002).

An investigation by Roberts and Kwan (2017) explored a common cognitive element within CBT: thought and belief challenging. They found that when people with ID were taught a range of cognitive challenging skills, through the means of extensive modelling, rehearsing, and prompting of strategies, they evidenced abilities to distinguish between helpful and unhelpful beliefs. The authors concluded that cognitive challenging can be beneficial for anxiety disorders and modifying unhelpful cognitions. However, a qualitative project by Haddock and Jones (2006) exploring practitioners views of CBT for people with ID concluded that only a small number of practitioners engage in CBT with this population, though a number of important aspects of CBT were touched upon, particularly the use of behavioural interventions over cognitive interventions. The preference for a behavioural intervention over that of a cognitive one may be due to the abstractness of cognitive therapy, but the paper fails to explore in depth practitioner's experience of cognitive therapy for people with ID.

A project by Marwood and colleagues (2016) focussed on the experiences of CBT practitioners delivering CBT to people with ID. Ten therapists took part in semi-structured interviews exploring their experiences of working with people with ID using CBT. Four key themes emerged, two of which were related to the larger systems (IAPT's agenda and service shortfalls), whilst the remaining two themes were in relation to the CBT model and the therapists themselves working with people with ID. It was reported that therapists appeared uncertain about how to modify CBT and highlighted training and service development needs. Marwood noted that therapists felt that they were out of their depth working with people with ID, and that they struggled working within the constraints of the CBT model, and that people with ID did not fit with a recovery model. Marwood concluded with a recommendation of specialist training and supervision to support IAPT therapists to develop their confidence and skills in delivering effective and appropriate interventions to people with ID, and that specialist ID services may be able to facilitate such support. Marwood also noted that there was a clear need for evidence-base and understanding regarding the specific components of CBT for people with ID.

The research has therefore evidenced some dissonance and confusion between why CBT is, and at times is not, offered to people with ID. Though a key theme is around the components of CBT and what elements are helpful and effective for people with ID. With this said, the aim of this qualitative paper is to build on the work by Haddock and Jones by exploring the experiences of practitioners working directly with people with ID, that have used, or attempted to use a CBT approach. The research question 'what are clinical practitioners experiences of CBT and it's components when working clinically with individuals diagnosed with an Intellectual Disability', reflects the aims of the project and will allow further understanding of the CBT model in relation to providing treatment to individuals with an ID. By doing so, this may allow practitioners within both primary and specialist mental health services to consider using the model when people with ID access their service.

2.3 Method

2.3.1 Study design

This project is a qualitative study comprising semi-structured, virtual interviews with CBT qualified practitioners.

2.3.2 Participants

Opportunity sampling was used using social media and word of mouth to target those practitioners adequately trained within a CBT approach and had used the model recently or historically, when working with people with ID. Research suggests a participant pool of 15-24 people is required to ensure data saturation (Vasileiou et al., 2018). A total of 47 practitioners initially came forward to participate in the study; however, following initial screening based on inclusion and exclusion criteria (**Table 3**), 15 participants were appropriate for the study. Participant characteristics are presented in **Table 4**.

Table 3: Inclusion and exclusion criteria for thematic analysis

Inclusion Criteria	Exclusion Criteria
Practitioners to be a minimum of one-year post qualification in a core profession where CBT has been implemented.	Practitioners unable to evidence adequate training in CBT, such as a Postgraduate Diploma in CBT, or a Doctorate in Clinical Psychology.
Practitioners to have a minimum of two-years practice with an ID population. This may include one-year unqualified in	Practitioners were not formally qualified (e.g., trainee Clinical Psychologists).
CBT, but must meet the above inclusion of one-year qualified.	Practitioners had limited experience of CBT with an ID population (i.e., less than 2 years' experience using
Working in primary or secondary care service, including private practice.	CBT with an ID population).
Adequately trained in CBT, such as a Postgraduate Diploma in CBT, or a Doctorate in Clinical Psychology.	
Registered with the British Association for Behavioural and Cognitive Psychotherapies (BABCP) or Health and Care Professions Council (HCPC).	

Note: for the purposes of this thesis submission, Table 3 has been included in the full write up. For the purposes of journal publication, it will be removed and added to the appendices as in line with the journal requirements.

Characteristics	Total n = 15	
Age (Mean, SD)	M = 40.1, SD = 4.9	
Reported Gender Identity		
Male	4	
Female	11	
Ethnicity		
White British	14	
White Other	1	
Qualification held		
Clinical Psychologist	14	
Clinical and Health Psychologist	1	
Years post qualification (Mean, SD)	M = 10.2, SD = 5.2	
Sector currently employed		
Public (NHS)	13	
Private	2	
Clinical setting currently employed		
Primary Care Services	1	
Specialist Services	14	

Table 4: Participant characteristics (n = 15)

Note: for the purposes of this thesis submission, Table 4 has been included in the full write up. For the purposes of journal publication, it will be removed and added to the appendices as in line with the journal requirements.

2.3.3 Interview schedule

The interview schedule employed for the project consisted of 14 questions exploring the participant's experiences of implementing a CBT approach with individuals that have ID (see appendix K), such as practitioner's perception applying the model, use of specific CBT components, formulation, and any perceived barriers. The interview schedule was initially developed by the research team, and later refined through a pilot-interview with a Counselling Psychologist with Postgraduate training in CBT, and a third-year trainee clinical psychologist. These pilot interviews have not been included in the data analysis.

2.3.4 Procedure

Ethics approval was granted by the University of Southampton (ERGO Number: 76884). Social media platforms were used for recruitment including Facebook and Twitter and through

word of mouth (i.e., known contacts through participants, researchers, and members of the British Psychology Society: Intellectual Disability Forum). Potential participants were screened to assess if they meet the inclusion and exclusion criteria by primary researcher. Prior to interviews commencing, participants received a participant information sheet and consent form (see appendix H and I). All consent forms were completed prior to the interviews taking place and were returned via email. Participants were given the option to attend the interview in person, or virtually using Microsoft Teams. Demographic information was initially collected, but not recorded to ensure anonymity. Interviews were recorded via an auditory dictation device or using Microsoft Teams and all information was stored securely in accordance with the associated University's data protection policy governing the use of personal data. All participants had the right to withdraw and withdraw any information or data held on them, three weeks after interviews were held. Following the completion of the interviews, participants received a debrief document (see appendix J) and a £10 voucher to reimburse their time. Interviews were then transcribed by the primary researcher.

2.3.5 Data analysis

Inductive thematic analysis followed the six-steps of systematic thematic analysis outlined by Braun & Clarke (2006). Following familiarisation of the data, notable features were grouped into codes in an attempt to capture ideas or perceptions of the participants. Identifying and analysing patterns of these codes resulted in creation of Themes, which were reviewed during the subsequent stage. This was a looping and recurrent process, where data was consistently checked against the themes created. Extracts were explored within supervision with the research team to ensure a degree of quality assurance, and remaining true to an inductive approach, in addition to consistency with a critical realist position assumed within this research. NVIVO (QSR International Pty Ltd., 2020) was used to aid in the completion of these steps and creation of coding manual (appendix L).

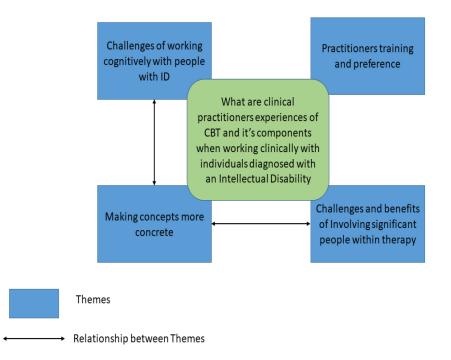
2.3.6 Reflexivity

The research team included the primary researcher being a third year Trainee Clinical Psychologist completing this project as part of their Doctorate in Clinical Psychology thesis, a qualified and chartered Clinical Psychologist (lead for the Doctorate in Clinical Psychology intellectual disability module), and a Research Psychologist (Doctorate in Clinical Psychology Deputy Research Director). The primary researcher had sufficient knowledge in thematic analysis and experiential experience previously provided through their doctorate training, whilst other members of the team had extensive practice in this field. In relation to clinical work with people with ID, two members of the team had direct clinical practice in a variety of settings designed for people with ID (e.g., community learning disability service). Furthermore, the primary researcher also had lived experiences of caring for young people and children with ID. It was explicit within the team that these clinical and lived experiences of working and caring for people with ID may pose potential biases and were often considered and discussed within regular supervision. The epistemology applied to this project was that of Critical Realist.

2.4 Results

The inductive thematic analysis identified four main themes as seen in **Figure 3** below: 1) Challenges of working Cognitively with people with ID, 2) Making concepts more concrete, 3) Practitioner's training and preference, 4) Challenges and benefits of Involving significant people within therapy.

Figure 3: Thematic map of themes and relationships between themes



2.4.1 Challenges of working cognitively with people with ID

Throughout the analysis it was noted that cognitive interventions could be useful and effective in modifying underlying beliefs and creating cognitive flexibility not only for the individuals with ID, but also for those supporting them. Techniques such as Theory A/B (catastrophic fear coming true versus a worry of a feared result, rather than a definite catastrophe) and Responsibility Pie (reflection on a situation as a whole, thinking about who and what else might have contributed to what happened/will happen) were also noted to be helpful tools when working on developing a cognitive shift, which may be supported by being able to use these techniques in a more concrete way:

"Cognitive therapy offers a route to look at attitudes to look at biases, so look at sort of expectations and there's a useful approach for the team setting as well." (P13)

"Theory A/B can be quite a nice sort of approach to take sort for just looking at kind of thought pattern they are you following and alternatives to these". (P4)

With this said, practitioners commented on a number of challenges they experienced whilst using cognitive exploration, understanding, and interventions. Practitioners noted that the concepts CBT explores and develops early in therapy, such as understanding cognitions, behaviours, feelings and emotions can be difficult for people with ID. This may be due to the deficit the individual experiences in line with their ID (thus potentially unable to grasp these concepts) or learning the link between the four elements which may take time to process and understand. As CBT is based fundamentally on this, they argue that being true to the model throughout therapy can be difficult:

> "Where you're looking at, kind of the prerequisite skills, so using a cognitive behaviour intervention so that basic event emotion link that people might be able to make that sense of modulating effect of affect or cognition. And if people aren't in any way able to make those kinds of links, you're stepping away from more true form CBT" (P3)

"Can be really tricky for people to actually pinpoint exactly where they hold a particular emotion...the cognitive part can be quite tricky for some people who are quite concrete or find that reflection side of things difficult at making links difficult." (P4)

This not only outlines the difficulties with abstract concepts, such as emotions and thoughts, but also language, and how people adapt language such as using metaphors to try to

explain the abstract concepts. Practitioners were also direct with how CBT-language can be unhelpful:

"I don't use a lot of the language that is from CBT, so I don't talk about thoughts, or things like catastrophising thoughts, or anything like that." (P6)

As noted, the use of abstract concepts and language that the 'cognitive' element of CBT includes can be a challenge when working cognitively with people with ID early on in therapy. When developing an understanding of a person's difficulties, it was noted that abstract concepts that CBT defines and uses can also interfere with how cognitive therapy is used as part of CBT, such as creating a joint formulation and interventions:

"...like a core belief or a schema. For someone with a learning disability, it's almost, It's too abstract, you know, so it's something that you can't necessarily expect them to ever appreciate or to ever sort of register." (P1)

"I don't know, the cognitive side of things like the negative automatic thoughts...some people can't connect quite well with this and can't do the diaries or don't identify with all of that." (P1)

Thus, there seems to be a number of challenges whilst working cognitively with people with ID and raises the question of how to enable practitioners and people with ID to engage with the CBT more successfully. Which is where the following theme around making concepts more concrete was also discovered within the analysis. It may also be that there are different 'levels' within these concepts in that some concepts may be easier to understanding (e.g., emotions) compared to that of more difficult and abstract concepts such as core beliefs.

2.4.2 Making concepts more concrete

The next theme that was discovered through analysis was that of making CBT concepts more concrete. Practitioners reflected on how behavioural interventions were useful, and at times more applicable, when working with people with ID due to how concrete they were. There seemed to be a more noticeable rationale and outcome when working behaviourally than cognitively as it is more concrete:

> "Behavioural work is kind of more applicable because it can be a bit more concrete for people to do graded hierarchies and stuff, and so I might do it more in that respect...I think it works really well." (P15)

"for me, I find that when working with people with learning disabilities, it is really hard to talk about things that is not in front of them. It is like asking someone to see something that's invisible" (P4)

Thus, it was important and helpful to place things visually in-front of the person with ID, making it more concrete. Further comments also support this when practitioners spoke about using concrete tasks and by drawing concepts out and explaining using visual aids during the session:

"Usually with pen and paper in front of them, drawing thought bubbles, drawing little stick men for behaviour. I will sit there with them and I'll talk them through it. So I think that's really helpful." (P2)

Abstract concepts were noted to be a challenge working cognitively with people with ID, and as a previous comment noted, being more concrete can be found more useful. Yet it was noted within the interviews that flexibility and creativeness can allow for notions to be concrete, which is more accessible to people with ID. Concepts such as mindfulness which can rely heavily on visualisation, can be made more concrete such as the 54321 technique, which was felt by practitioners as a way to make sense to those people with ID:

"The best I would say out of all of them is the 54321... Often find people can actually engage with it's quite short and it's quite it makes sense to people quite quickly" (P1)

"I think the difficulty is to try to make the links with what's happened before or what's going to happen later, but I think people connect really well with that sense of being okay. What we are and connect with, what you are feeling at this moment in time and how, you know, the sensory component of that... moving on through the soles of the feet kind of meditations and that sort of thing that people really connect with...I think that's really useful." (P5)

However, though this last quote can seem contradictory, particularly in relation to what is going on for the person in the moment, such as thoughts and emotions, it may be that the bodily response the individual is experience, along with behaviours and behavioural urges are a concrete experience people with ID can use.

2.4.3 Practitioner's training and preference

Participants interviewed for this study were qualified Clinical Psychologists, and as part of their clinical training would have had some academic and clinical experience of applying CBT.

36

However, a speculative barrier, and enabler, for people with ID accessing individual CBT appears to be related to the practitioners training and/or preference with the CBT model. It may be that the practitioner may have completed their training a long time ago, which might mean that the training course they undertook was not so focussed on CBT or just their personal preference when working with people with ID:

> "But I think it's probably more to do sometimes with the therapist...the skills, expertise and what they are interested in, and some people might not want to do CBT because of this." (P6).

"I did my training a long time ago, and CBT wasn't pushed as much as training courses do today, so I guess it's not really my go-to". (P8).

Alternatively, it may also be that practitioners that have undergone training more recently may be more prone to applying a CBT model. Furthermore, analysis indicated that there may be an overall cultural view of CBT within particular fields or training for Clinical Psychologists, which as a consequence may have results in fewer practitioners suggesting a CBT approach for the individual with ID:

> "We had lots training on it, but it was almost presented in quite a negative way in some respects, and I think that's because yeah of all the political situation that was going on around it at the time." (P3).

"When I think of CBT I usually think of coping skills you can teach quickly, rather than exploring underlying beliefs and concepts. I much more prefer Mindfulness and building an understanding of people's difficulties with attachments to others" (P7).

2.4.4 Challenges and benefits of Involving significant people within therapy

A theme around the support people with ID have from significant others whilst accessing CBT also emerged from the data. A number of practitioners stated that staff and carers' support impacted not only the logistical issues such as attending the appointment and reminding the individuals about the appointment, but also the potential effectiveness of the sessions such as any systemic agendas or communication with colleagues.

> "It could be that you've told that to the staff member who's with them in this session and then they go home and maybe it doesn't get passed on. So, it's the communication" (P12).

"Often relying on staff, some staff are great and they're really into the therapy to support the person; Um, but others, they may have their own issues and agenda's and maybe don't support the individual with the therapy" (P3).

Yet equally it was also found that involving the staff/families within the therapy session came with benefits. These benefits were reported to include the staff/family understanding the difficulties for the person with ID, which in turn may disrupt how staff respond to the individual's difficulties. Moreover, it was also noted to develop the staff's perspective of the individual, and thus create a shift psychologically, emotionally and behaviourally, such as staff being able to see why the individual presents the way they do, in addition to staff feeling more empathy around the person.

> "I also think It can be really helpful for carers, for families and staff helping them understand sometimes what's going on....especially when considering how they respond" (P9)

"he lives in a residential service so we shared his formulation with the staff team that support him, and that's been really helpful because staff did say they don't understand why he does this." (P1)

"Um, it also gives the staff capacity to build empathy for people with learning disability, who the teams might be dealing with." (P5)

Involving staff and/or families within the therapy sessions for the service users may also provide assistance not only in reducing the abstractness that cognitive therapy involves by providing more concrete and relatable examples (i.e., care staff will know the client better), but also with implementation of homework/between-session tasks (e.g., accessing the community for activity-scheduling tasks).

2.5 Discussion

An inductive thematic analysis was used within this project to explore what clinical practitioners' experiences of CBT are, and its components when working clinically with individuals diagnosed with an Intellectual Disability. Similarly, to that of Interpretative Phenomenological Analysis (IPA), thematic analysis is used as a reflexive and inductive tool to explore overarching patterns across a dataset, that being practitioners' experiences. Though thematic analysis explores the dataset as a whole, as compared to IPA where focus is on each individual's experience and thus, providing a more rich and deep understanding of their experiences. Thematic analysis provides the opportunity to extract themes that can be generalized to broader contexts and populations, which was key for this project in not only extracting but also promoting the findings of practitioners' experiences to those working with individuals with ID. With this said, the thematic analysis identifies some of the potential components that CBT has to offer for people with ID, and where challenges may arise. The challenges of cognitive therapy, concreteness, involving significant others, and overall impact practitioners training and preference may have on offering the model to people with ID were the key themes identified. This therefore adds insight into the elements of CBT that have not previously been well-understood for people with ID (Bekirogullari, 2018; Jennings & Hewitt, 2015) and further builds on the work by Haddock & Jones (2006).

Haddock and Jones (2006) concluded within their work investigating practitioner's consensus and views of CBT for people with ID, that adapting CBT was key for this population, and that creativity supported this, particularly around making concepts more concrete such as using visual aids and tools. Though the adaptations identified by Haddock and Jones were mainly targeted for people with ID and comorbidities (e.g., Autism Spectrum Disorder), the results from this report do support their findings. The results from this investigation identified that working more concretely enables people with ID to further understand and connect with the CBT model. This finding may also replicate the findings of Dagnan et al., (2018) in that they found behavioural interventions an effective way for enabling positive change and managing symptoms of anxiety and depression, which may be due to the concreteness of this approach. Support for the use of cognitive interventions were also reinforced in this study, in which practitioners found techniques such as responsibility pie and Theory A/B were useful; however, there does seem to be some cognitive elements, such as making links between emotions, behaviours, thoughts, and body which are more difficult; along with the avoidance of thought challenging techniques due to their level of abstractness.

Research by Roberts and Kwan (2017) investigating cognitive interventions for people with ID found that levels of anxiety were reduced when people with ID were taught how to challenge unhelpful thoughts. However, this does not seem to translate into the clinical experiences of practitioners, as a number of participants noted to avoid cognitive interventions, particularly techniques such as thought challenging, primarily due to the abstractness of this approach. The potential dissonance between research and clinical experience may be a consequence of diagnostic overshadowing, in that some cognitive techniques are typically avoided due to them being abstract and people with ID often finding abstract thinking more difficult, which has been a common contributor for practitioners working with mental health difficulties in the ID population (Mason & Scior, 2004). Though the cognitive aspect of CBT may be abstract, making these more concrete and providing allowances so that people with ID can develop an understanding of abstract concept could be an alternative way to working cognitively with this population.

The results of this project also indicated a number of potential barriers hindering people with ID in accessing individual CBT therapy, such as the importance of involving staff and carers, whilst implementing a CBT approach. This has also been previously noted by Stenfert-Kroese et al., (2014), who found systemic supports were key to ensuring the maintenance and generalisation of improved psychological well-being. This finding was also outlined by Haddock and Jones (2006). However, not only did this current research replicate these findings but also indicated that allowing significant others to attend and understand the person's difficulties is beneficial due to shifting staff perspectives of the individual, developing empathy and changing how staff respond to service users.

This current research project also goes further than others discussed in not only identifying the cognitive elements of CBT, but also further exploring additional systemic influences such as practitioners training and preferences. This potential barrier to offering CBT for people with ID is also discussed by Marwood and colleagues (2018) as part of their qualitative research of high intensity therapists (CBT therapists providing individual therapy) working with this population. They found that practitioner's confidence in working with individuals with ID, views of CBT and how to adapt the CBT model for this population were potentially associated with, but not the sole cause of, people accessing CBT interventions within IAPT. Marwood et al., noted that within their project, practitioners found working within the constraints of the CBT model difficult, particularly due to the complexity of ID, and the knowledge and experience of adapting CBT could be advantageous. This was a similar overall concept with the population for this project, though these were practitioners from more specialist services and different clinical profession; yet, they too felt that following rigid formulation-treatment plans difficult for people with ID. It was reported within this project that small adaptations to the CBT model were easily achievable (e.g.,

40

concreteness) which did not get reported by those participants in Marwood et al. It may be that not only what Marwood and colleagues recommended, that being specialist training and supervision for IAPT staff to support staff developing confidence and skills working with the ID population; but also, how training programs for IAPT practitioners can focus on elements that are easily achievable, such as adapting therapy for this population and working with significant other members around the individual.

2.5.1 Limitations of study

Throughout this investigation there appears to be a number of limitations to consider. The participants recruited within this project were 15 Clinical Psychologists, and unfortunately, it was not possible to recruit other health professionals that also offer CBT at an appropriately trained level (e.g., high intensity Cognitive Behavioural Therapists). As a result, this not only makes the findings of this report difficult to apply to CBT practitioners that are not Clinical Psychologists, but it also means that the experiences collated for this project may have been biased with the application of CBT for ID. Moreover, the participants recruited were also similar ethnically, which also limits the generalisability of the results. A further point in relation to the participants recruited is that a vast majority of them were in active roles within specialist services for people with ID. This initially differentiates it from the work of others, such as Marwood et al., (2018), not only in regards to participants' profession, but also the service they were at the time employed at; yet it would have been advantageous to have collected historical employment experience for participants as it was unclear whether they were utilising experience from primary care, specialist services or an amalgamation of both when recalling their experiences of using CBT for people with ID. Reflecting on how data was analysed for this project, that being thematic analysis. It could be argued that it would have been more beneficial to utilise an Interpretative Phenomenological Analysis (IPA) approach when extracting and analysing the dataset. Though there are similarities between both approaches, IPA may have been able to provide a more detailed understanding of each practitioner's experiences of CBT ID.

A further valid limitation to this report is that this study was conducted in early 2023, which was not too long after the Covid-19 pandemic, which may result in the participants providing experiences of CBT and ID during the pandemic, where a large number of healthcare workers provided interventions virtually online, or if in person, utilised personal protective clothing including face masks. All of which may have influenced the experiences of using CBT with people with ID. Furthermore, the interviews for this project were conducted over Microsoft Teams due to time constraints and availability of participants. As a consequence, it was not possible to monitor

41

the environment the participants were conducting their interview. In-person interviews in a controlled environment would have been more advantageous.

2.5.2 Clinical implication & future research

Following on from this paper, interesting future research may include exploring the concept of diagnostic overshadowing when people with ID access talking therapies, eligibility and barriers for people with ID accessing CBT at primary level services, and the views and opinions of people with ID when a CBT model has been implemented. Further exploration in these areas will provide more insight into how cognitive interventions can be made more efficient and accessible for people with ID and additional barriers that this population may face, such as diagnostic overshadowing. It may also be useful for practitioners in specialist services to be more aware of the model of therapy they offer to people with ID in relation to the above, but also to consider providing support and guidance (via clinical supervision) to other health care practitioners using a CBT model in primary care services.

2.5.3 Conclusion

This research paper explores the use of CBT with people with ID in a novel way by reviewing the experience of practitioners working directly with individuals with ID whilst using the CBT model. By exploring different elements of the CBT model and its application, major concepts were identified that can be helpful in providing positive treatment outcomes when working with individuals with ID. Important themes include the challenges of working cognitively with people with ID, the importance of making concepts more concrete, practitioners training and preference when offering CBT, and challenges and benefits of involving significant others within therapy. This project has not only been able to reiterate previous research, but also raise some new and interesting research topics for future work, such as research into diagnostic overshadowing, eligibility to accessing CBT at a primary care level, and people with ID's views of accessing CBT. All of which will support people with ID to access mental health services, where barriers are reduced and adaptations made so they can have a variety of options of treatment available to them and that they are able to fully access.

International Journal of Developmental Disabilities

Instructions for authors

About the Journal

International Journal of Developmental Disabilities is an international, peer-reviewed journal publishing high-quality, original research. Please see the journal's <u>Aims &</u> <u>Scope</u> for information about its focus and peer-review policy. Please note that this journal only publishes manuscripts in English. International Journal of Developmental Disabilities accepts the following types of article: Original/Review articles Points of View articles Letters to the Editor

Open Access

You have the option to publish open access in this journal via our Open Select publishing program. Publishing open access means that your article will be free to access online immediately on publication, increasing the visibility, readership and impact of your research. Articles published Open Select with Taylor & Francis typically receive 45% more citations* and over 6 times as many downloads** compared to those that are not published Open Select.

Your research funder or your institution may require you to publish your article open access. Visit our <u>Author Services</u> website to find out more about open access policies and how you can comply with these.

You will be asked to pay an article publishing charge (APC) to make your article open access and this cost can often be covered by your institution or funder. Use our <u>APC finder</u> to view the APC for this journal.

Please visit our <u>Author Services website</u> if you would like more information about our Open Select Program.

*Citations received up to 9th June 2021 for articles published in 2018-2022. Data obtained on 23rd August 2023, from Digital Science's Dimensions platform, available at <u>https://app.dimensions.ai</u> **Usage in 2020-2022 for articles published in 2018-2022.

Peer Review and Ethics

Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. Once your paper has been assessed for suitability by the editor, it will then be single anonymous peer reviewed by one independent, anonymous expert. If you have shared an earlier version of your Author's Original Manuscript on a preprint

server, please be aware that anonymity cannot be guaranteed. Further information on our preprints policy and citation requirements can be found on our <u>Preprints Author</u> <u>Services page</u>. Find out more about <u>what to expect during peer review</u> and read our guidance on <u>publishing ethics</u>.

Preparing Your Paper

All authors submitting to medicine, biomedicine, health sciences, allied and public health journals should conform to the <u>Uniform Requirements for Manuscripts Submitted to</u> <u>Biomedical Journals</u>, prepared by the International Committee of Medical Journal Editors (ICMJE).

Article Types

Original/Review articles

Should be written with the following elements in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list)

Should be no more than 7000 (although longer manuscripts may be considered in consultation with the editors) words, inclusive of:

- References
- Figure or table captions

Should contain a structured abstract of 200 words.

Abstracts should preferably be structured, although unstructured abstracts are also allowed.

Should contain between 5 and 8 keywords. Read <u>making your article more discoverable</u>, including information on choosing a title and search engine optimization. Review and Original article authors should provide sufficient background information to allow both specialists and non-specialists working with those with intellectual disabilities to gain both knowledge and perspective of all aspects on the habilitation of those with intellectual disabilities. The editors emphasise their interest in publication of articles that present a critical review of previous findings, as opposed to a simple compilation of previously published data and interpretations. Areas of interest to the Journal include; authoritative reviews on topics such as the causes, diagnosis, care, therapeutic intervention, learning strategies, challenging behaviour, improvement of quality of life, medication etc.

Review articles may also include; Systemic review/Meta-analysis, which must also include a statistical technique for quantitatively combining the results of multiple studies that measure the same outcome into a single pooled or summary estimate. Please refer to the <u>PRISMA reporting guidelines for guidance</u>.

All articles or data sources should be searched for and selected systematically for inclusion and critically evaluated, and the search and selection process (key words used etc) should be described in the manuscript.

The specific type of study or analysis, population, intervention, exposure, and tests or

outcomes should be described for each article or data source. The data sources should be as current as possible. Manuscripts should present systematic, critical assessments of literature and data sources pertaining to intellectual disabilities and also emphasise factors in areas of interest such as the causes, diagnosis, care, therapeutic intervention, learning strategies, challenging behaviour, improvement of quality of life, medication etc.

Points of View articles

- Should be written with the following elements in the following order:
- Should be no more than 3,500 words

"Points of View" articles present preliminary findings or report studies that are not statistically significant or new hypotheses with or without data. They may be organised like Original/Review articles but do not have to be. They may or may not have an abstract, at the authors and editors discretion. These articles should have a maximum of 3,500 words in length (although longer manuscripts may be considered in consultation with the editors).

Letters to the Editor

Should be written with the following elements in the following order:

Should be no more than 1000 words

These are generally short letters about published papers, new ideas, re-interpretation of data, topical news in the area of intellectual disabilities etc. They should be limited to 1,000 words.

Style Guidelines

Please refer to these <u>quick style guidelines</u> when preparing your paper, rather than any published articles or a sample copy.

Any spelling style is acceptable so long as it is consistent within the manuscript. Please use single quotation marks, except where 'a quotation is "within" a quotation'. Please note that long quotations should be indented without quotation marks.

Alt Text

This journal is now including Alt Text (alternative text), a short piece of text that can be attached to your figure to convey to readers the nature or contents of the image. It is typically used by systems such as pronouncing screen readers to make the object accessible to people that cannot read or see the object, due to a visual impairment or print disability.

Alt text will also be displayed in place of an image, if said image file cannot be loaded. Alt Text can also provide better image context/descriptions to search engine crawlers, helping them to index an image properly.

To include Alt Text in your article, please follow our Guidelines.

Formatting and Templates

Papers may be submitted in Word or LaTeX formats. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting template(s). <u>Word templates</u> are available for this journal. Please save the template to your hard drive, ready for use.

A <u>LaTeX template</u> is available for this journal. Please save the LaTeX template to your hard drive and open it, ready for use, by clicking on the icon in Windows Explorer. If you are not able to use the template via the links (or if you have any other template

queries) please contact us here.

References

Please use this <u>T&F standard Chicago author-date reference style</u> when preparing your paper. An <u>EndNote output style</u> is also available to assist you.

Taylor & Francis Editing Services

To help you improve your manuscript and prepare it for submission, Taylor & Francis provides a range of editing services. Choose from options such as English Language Editing, which will ensure that your article is free of spelling and grammar errors, Translation, and Artwork Preparation. For more information, including pricing, <u>visit this website</u>.

Checklist: What to Include

Author details. Please ensure everyone meeting the International Committee of Medical Journal Editors (ICMJE) <u>requirements for authorship</u> is included as an author of your paper. Please ensure all listed authors meet the <u>Taylor & Francis authorship criteria</u>. All authors of a manuscript should include their full name and affiliation on the cover page of the manuscript. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. <u>Read more on authorship</u>.

Graphical abstract (optional). This is an image to give readers a clear idea of the content of your article. For the optimal online display, your image should be supplied in landscape format with a 2:1 aspect ratio (2 length x 1 height). Graphical abstracts will often be displayed online at a width of 525px, therefore please ensure your image is legible at this size. Save the graphical abstract as a .jpg, .png, or .tiff. Please do not embed it in the manuscript file but save it as a separate file, labelled GraphicalAbstract1.

You can opt to include a **video abstract** with your article. <u>Find out how these can help</u> your work reach a wider audience, and what to think about when filming.

Funding details. Please supply all details required by your funding and grant-awarding bodies as follows:

For single agency grants

This work was supported by the [Funding Agency] under Grant [number xxxx]. *For multiple agency grants*

This work was supported by the [Funding Agency #1] under Grant [number xxxx]; [Funding Agency #2] under Grant [number xxxx]; and [Funding Agency #3] under Grant [number xxxx].

Disclosure statement. This is to acknowledge any financial or non-financial interest that has arisen from the direct applications of your research. If there are no relevant competing interests to declare please state this within the article, for example: *The*

authors report there are no competing interests to declare. <u>Further guidance on what is a</u> conflict of interest and how to disclose it.

Supplemental online material. Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about <u>supplemental material</u> and how to submit it with your article.

Figures. Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour, at the correct size). Figures should be supplied in one of our preferred file formats: EPS, PS, JPEG, TIFF, or Microsoft Word (DOC or DOCX) files are acceptable for figures that have been drawn in Word. For information relating to other file types, please consult our <u>Submission of electronic artwork</u> document.

Tables. Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.

Equations. If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about <u>mathematical symbols and</u> <u>equations</u>.

Units. Please use SI units (non-italicized).

Using Third-Party Material

You must obtain the necessary permission to reuse third-party material in your article. The use of short extracts of text and some other types of material is usually permitted, on a limited basis, for the purposes of criticism and review without securing formal permission. If you wish to include any material in your paper for which you do not hold copyright, and which is not covered by this informal agreement, you will need to obtain written permission from the copyright owner prior to submission. More information on <u>requesting permission to reproduce work(s) under copyright</u>.

Disclosure Statement

Please include a disclosure statement, using the subheading "Disclosure of interest." If you have no interests to declare, please state this (suggested wording: *The authors report there are no competing interests to declare*). For all NIH/Welcome-funded papers, the grant number(s) must be included in the declaration of interest statement. <u>Read more on declaring conflicts of interest</u>.

Clinical Trials Registry

In order to be published in a Taylor & Francis journal, all clinical trials must have been registered in a public repository, ideally at the beginning of the research process (prior to participant recruitment). Trial registration numbers should be included in the abstract, with full details in the methods section. Clinical trials should be registered prospectively – i.e. before participant recruitment. However, for clinical trials that have not been registered prospectively, Taylor & Francis journals requires retrospective registration to ensure the transparent and complete dissemination of all clinical trial results which ultimately impact human health. Authors of retrospectively registered trials must be prepared to provide further information to the journal editorial office if requested. The

clinical trial registry should be publicly accessible (at no charge), open to all prospective registrants, and managed by a not-for-profit organization. For a list of registries that meet these requirements, please visit the <u>WHO International Clinical Trials Registry</u> <u>Platform</u> (ICTRP). The registration of all clinical trials facilitates the sharing of information among clinicians, researchers, and patients, enhances public confidence in research, and is in accordance with the <u>ICMJE guidelines</u>.

Complying with Ethics of Experimentation

Please ensure that all research reported in submitted papers has been conducted in an ethical and responsible manner, and is in full compliance with all relevant codes of experimentation and legislation. All original research papers involving humans, animals, plants, biological material, protected or non-public datasets, collections or sites, must include a written statement in the Methods section, confirming ethical approval has been obtained from the appropriate local ethics committee or Institutional Review Board and that where relevant, informed consent has been obtained. For animal studies, approval must have been obtained from the local or institutional animal use and care committee. All research studies on humans (individuals, samples, or data) must have been performed in accordance with the principles stated in the <u>Declaration of Helsinki</u>. In settings where ethics approval for non-interventional studies (e.g. surveys) is not required, authors must include a statement to explain this. In settings where there are no ethics committees in place to provide ethical approval, authors are advised to contact the Editor to discuss further. Detailed guidance on ethics considerations and mandatory declarations can be found in our Editorial Policies section on <u>Research Ethics</u>.

Consent

All authors are required to follow the <u>ICMJE requirements</u> and <u>Taylor & Francis Editorial</u> <u>Policies</u> on privacy and informed consent from patients and study participants. Authors must include a statement to confirm that any patient, service user, or participant (or that person's parent or legal guardian) in any type of qualitative or quantitative research, has given informed consent to participate in the research. For submissions where patients or participants can be potentially identified (e.g. a clinical case report detailing their medical history, identifiable images or media content, etc), authors must include a statement to confirm that they have obtained written informed consent to publish the details from the affected individual (or their parents/guardians if the participant in not an adult or unable to give informed consent; or next of kin if the participant is deceased). The process of obtaining consent to publish should include sharing the article with the individual (or whoever is consenting on their behalf), so that they are fully aware of the content of the article before it is published. Authors should familiarise themselves with our <u>policy on</u> <u>participant/patient privacy and informed consent</u>. They may also use the Consent to Publish Form, which can be downloaded from the <u>same Author Services page</u>.

Health and Safety

Please confirm that all mandatory laboratory health and safety procedures have been complied within the course of conducting any experimental work reported in your paper. Please ensure your paper contains all appropriate warnings on any hazards that may be involved in carrying out the experiments or procedures you have described, or that may be involved in instructions, materials, or formulae. Please include all relevant safety precautions; and cite any accepted standard or code of practice. Authors working in animal science may find it useful to consult the <u>International Association of Veterinary Editors' Consensus Author Guidelines on Animal Ethics and Welfare and Guidelines for the Treatment of Animals in Behavioural Research and Teaching</u>. When a product has not yet been approved by an appropriate regulatory body for the use described in your paper, please specify this, or that the product is still investigational.

Submitting Your Paper

This journal uses Taylor & Francis' <u>Submission Portal</u> to manage the submission process. The Submission Portal allows you to see your submissions across Taylor & Francis' journal portfolio in one place. To submit your manuscript please click <u>here</u>.

If you are submitting in LaTeX, please convert the files to PDF beforehand (you will also need to upload your LaTeX source files with the PDF).

Please note that *International Journal of Developmental Disabilities* uses <u>Crossref™</u> to screen papers for unoriginal material. By submitting your paper to *International Journal of Developmental Disabilities* you are agreeing to originality checks during the peer-review and production processes.

On acceptance, we recommend that you keep a copy of your Accepted Manuscript. Find out more about <u>sharing your work</u>.

Publication Charges

There are no submission fees, publication fees or page charges for this journal. Color figures will be reproduced in color in your online article free of charge. If it is necessary for the figures to be reproduced in color in the print version, a charge will apply.

Charges for color figures in print are £300 per figure (\$400 US Dollars; \$500 Australian Dollars; €350). For more than 4 color figures, figures 5 and above will be charged at £50 per figure (\$75 US Dollars; \$100 Australian Dollars; €65). Depending on your location, these charges may be subject to local taxes.

Copyright Options

Copyright allows you to protect your original material, and stop others from using your work without your permission. Taylor & Francis offers a number of different license and reuse options, including Creative Commons licenses when publishing open access. <u>Read</u> more on publishing agreements.

Complying with Funding Agencies

We will deposit all National Institutes of Health or Wellcome Trust-funded papers into PubMedCentral on behalf of authors, meeting the requirements of their respective open access policies. If this applies to you, please tell our production team when you receive your article proofs, so we can do this for you. Check funders' open access policy mandates <u>here</u>. Find out more about <u>sharing your work</u>.

My Authored Works

On publication, you will be able to view, download and check your article's metrics (downloads, citations and Altmetric data) via <u>My Authored Works</u> on Taylor & Francis Online. This is where you can access every article you have published with us, as well as

your <u>free eprints link</u>, so you can quickly and easily share your work with friends and colleagues.

We are committed to promoting and increasing the visibility of your article. Here are some tips and ideas on how you can work with us to <u>promote your research</u>.

Queries

If you have any queries, please visit our <u>Author Services website</u> or contact us <u>here</u>. Updated 22nd February 2024

Appendix B

Doctorate in Clinical Psychology Cover Sheet

Student Number	31125727			
Module Code and Name	PSYC8047			
Cohort Year	2020			
Submission Date	22/03/2024			
Assignment Title	Reviewing and developing on interventions for managing			
	behavioural and mental health difficulties for people with			
	intellectual disabilities			
Word Count	Total: 12321			
	Systematic Review: 6575			
	Empirical Project: 5746			
	Academic Integrity			
By sub	mitting this assignment, I confirm that:			
1. I have read and und	erstood the University's Academic Integrity Guidance for Students			
and that in the attached su	ubmission I have worked within the expectations of the Regulations Governing Academic Integrity.			
	ure to act in accordance with the <u>Regulations Governing Academic</u> le imposition of penalties which, for the most serious cases, may include termination on the programme.			
using third parties (wh	ersity copying and distributing any or all of my work in any form and o may be based outside the EU/EEA) to verify whether my work giarised material, and for quality assurance purposes.			
	Clinical Confidentiality			
In sub	mitting this assignment, I confirm that:			
	ifiable information has been removed in line with data protection <u>ection Act 2018</u>) and NHS guidance (e.g. <u>NHS Code of Practice for</u> <u>Confidentiality 2003</u>).			
	n changed and replaced with pseudonyms in order to protect the carers and family, as well as the services and other professionals involved.			
 I have been explicit in explaining any anomaly which might cause uncertainty as to whether confidentiality has been maintained (i.e., where working with clients with multiple names). 				
4. Client consent has been obtained in line with <u>BPS Practice Guidance (2017)</u> to authorise the use of the work for educational purposes. This has been recorded in the clients clinical record and confirmed by the placement supervisor.				
Quality Handbook. If you require	rity Regulations and Guidance can be accessed via the <u>University</u> any further guidance about academic integrity please talk to your tact the library via <u>LibGuide@Southampton</u> .			
	es may be used anonymously as examples for other cohorts. Please signment if you do NOT want your work to be used for this purpose.			

Appendix C

Date	Reflection	Reflection
	from	
21/12/22	First review	This is my first time reviewing this paper, and have many thoughts. It
21/12/22		
	of paper:	is such an interesting paper specifically looking at parents' views of
	Elford, H.,	applying restrictive practices when caring for their loved ones. The
	Beail, N., &	paper used IPA and I am wondering why they chose this approach and
	Clarke, Z.	am wondering if it is primarily due to what the authors notes as 'small
	(2010).	sample'. It will be worth exploring this further in supervision. The
		sample size of the study also includes more women than men, and I
		wonder if this will somehow bias the data. My initial thoughts are
		around gender differences in men and women with challenging
		behaviours and presentation of these. Are certain types of challenging
		behaviours more prone to having restrictive practices applied? Or are
		my own personal and professional experiences interfering with this?
		As a healthcare professional myself, when reading this paper I find
		myself regularly reflecting on my approach with the people I work
		with, and have worked with previously, and my interactions with
		family members. I find my 'pulls' being directed towards maintaining
		safety (everyone involved), whilst also being aware that I do not know
		the situations they are placed in. Again, potential biases I may hold an
		would be worth speaking about in supervision with the research team.
		A final point, I wonder why of all the papers there is only this one that
		include family members views. Is this an area of future research to
		recommend?
02/12/22	Following	The supervision session was extremely helpful but left me wondering the usefulness of the CASP tool. Having read the papers myself and
	Supervision	reviewing their quality with the CASP, it was not always clear how to
	with	provide a definitive score/grade for some sections within the CASP. I do feel that the CASP tool has helped me gain more insight into the

Excerpts from Reflective Journal Log

Appendix C

Research Team	papers themselves, and has also allowed me to identify where some papers can be improved (e.g., gender biases; identifying research questions), however, I realise that there are opportunities to rate a paper unfairly. It is possible that having been submerged within the data, regularly reading, re-reading and reviewing them, that the scores I provided the papers is only a reflection of my own lens, and ultimately also including some of my own biases. This supervision session around these CASP scores not only allowed me to challenge some of these biases (e.g., if the research design was appropriate to address the aims of report), but also identify biases linked to my own personal experiences (e.g., gender differences and restrictive practices) which I was not aware of before. Also, how do I 'keep-check' of this going forward. Moreover, it has also identified to me area's that I need to do some further reading and research around, such as papers explicitly stating their relationship with their project, the population they work in and the purpose of their project.
------------------	--

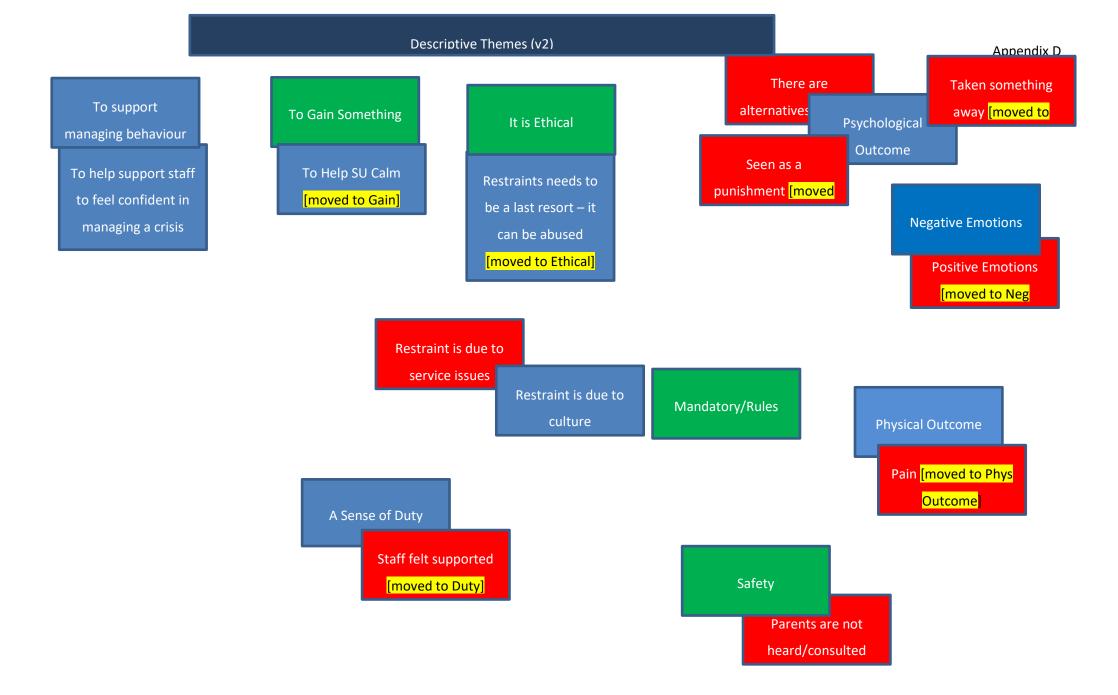
Appendix D

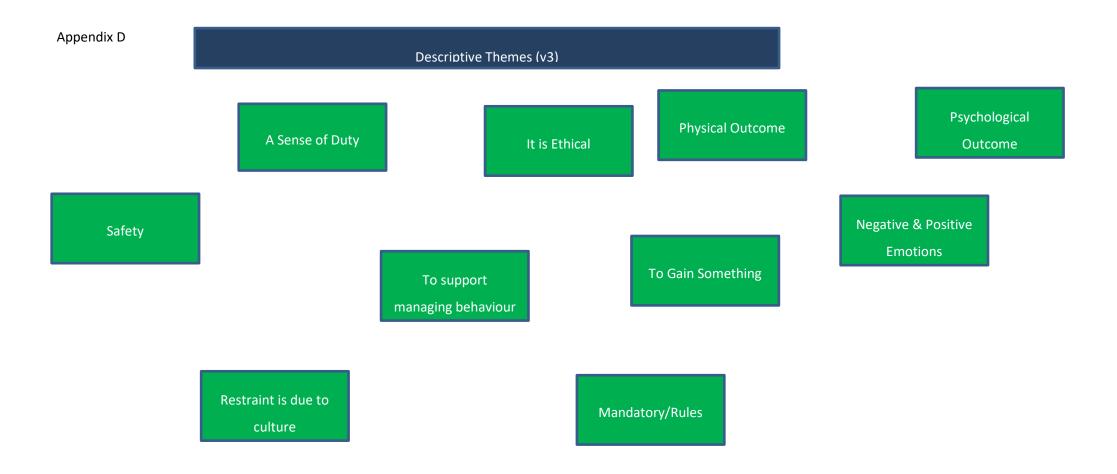
Creation of Descriptive and Analytical Themes

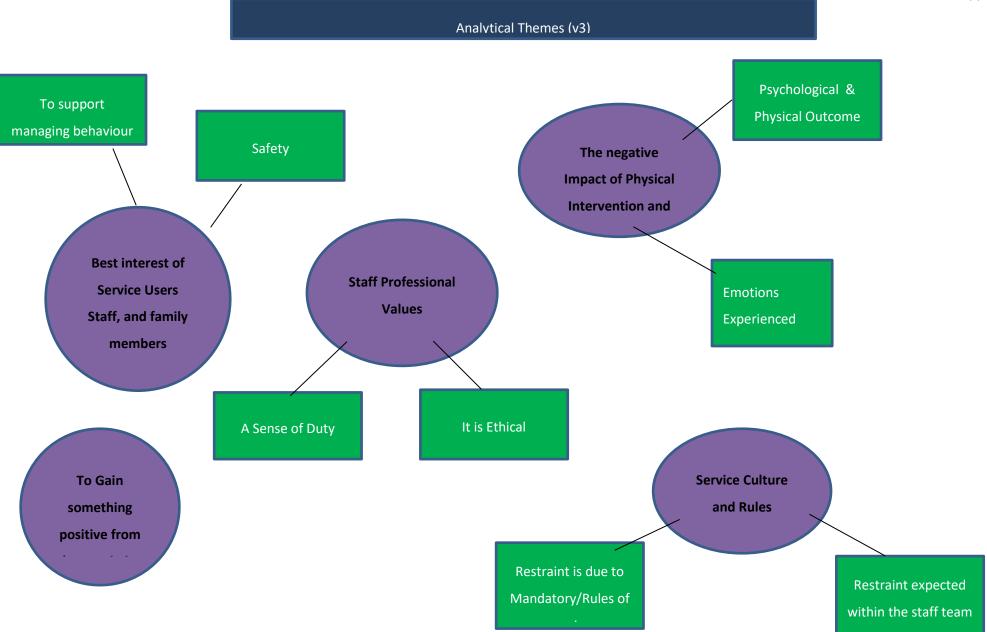


Red Fill = very little codes recorded (<5 codes)

Blue = between 5-10 codes **Green = heavily populated with codes (>10 Codes)**







Appendix D

59

Appendix E

Appendix E

Systematic Review: Coding Manual

A thematic synthesis collating the experiences of staff members, family members, and individuals with intellectual disabilities on the application of restrictive interventions within community-based residences

Theme	Subtheme (if	Description of theme	Codes included	Example Quotes
	relevant)	(or subtheme if using subthemes)	(bullet point)	
Gain something positive		Service users gain something from the	Service user had	"For one staff member, the use of a
from restrictive practice		Restrictive Practice: physical and	more contact with	restrictive measure also had positive
		psychological comfort; interaction.	staff member	consequences such as an increased
				frequency of contacts with the user."
		Staff members also gain from Restrictive		(Mérineau-Côté & Morin, 2014: author).
		Practice: interaction; reduction of		
		challenging behaviours (risk of injury)	Staff member	"She [person with ID] relaxes into you
			provides comfort	[staff] holding her like thatShe wants

Theme	Subtheme (if relevant)	Description of theme (or subtheme if using subthemes)	Codes included (bullet point)	Example Quotes
			[following Restrictive Practice]	you to be holding her." (Hawkins et al., 2005: staff)
			Service user feels comfortable [following Restrictive Practice]	"Comment made by a service user was related to comfort and came from service user 1. In response to the question 'How does your body feel?', she replied 'comfortable'. (Hawkins et al., 2005: author and person with ID).
Staff professional values	A sense of duty	Staff members: feel sense of duty to being a healthcare worker; what the job entails; the potential negative consequences of not fulfilling their duty; sense of being unable to do what they feel they 'want'	It is my job to ensure service users don't lose.	"If it can be avoided in any way, whatsoever then that's our job, because the service user loses twice, don't they?" (Ravoux et al., 2012: staff).

Theme	Subtheme (if relevant)	Description of theme (or subtheme if using subthemes)	Codes included (bullet point)	Example Quotes
		(e.g., walking away) versus what they 'have to do'	I have to do it [Restrictive Practice]. It's my job	"I can't walk away, this is my job." (Hawkins et al., 2005: staff).
	It is ethical.	Sense of intervening at most appropriate (and ethical) time. Least negative impact of two options (e.g., burn hand versus restraint). Understanding that restraint/restrictive interventions impact power-balance, which can be misused.	Restrictive Practice is more ethical	"So there are times when it's necessary if a person isn't aware of what can happen. You know, if someone's gonna put their hand in the fire you wouldn't just watch and not do anything". (Elford, et al., 2010: Parent).
			Restraint is ethical. It can be misused	"The power in restraint, and potential for misuse of this was highlighted." (Elford, et al., 2010: author).

Theme	Subtheme (if	Description of theme	Codes included	Example Quotes
	relevant)	(or subtheme if using subthemes)	(bullet point)	
Negative impact of		A variety of physical, psychological &	Restraint is	"However, this is uncomfortable for him.
physical interventions and		emotional impact of restraint/restrictive	uncomfortable for	He doesn't think it is necessary." (Van der
restrictive practices		practice. Service users: uncomfortable	service user	Meulen et al., 2018: staff).
		during; confusion, guilt, sadness, anger,		
		irritability. Staff feel relief, following the		"[Interviewer] How did that used to make
		ending of restrictive practices: "walking on	Service user felt sad	you feel? [Service user] Sad. [Interviewer]
		eggshells", potential anxiety prior to	[following	How did your body feel when you were
		intervention and relief after.	Restrictive Practice]	on the floor? [Service user] It hurt on the
				floor". (Hawkins et al., 2005: person with
				ID).
			Service user feels	"[author] During the Physical Intervention
			guilt [Psychological	relates strongly to their beliefs about, and
			impact]	experiences of, service user behaviour.
				Service user: Probably fed upfed up

Theme	Subtheme (if relevant)	Description of theme (or subtheme if using subthemes)	Codes included (bullet point)	Example Quotes
			Staff feel relief [following Restrictive Practice] Service user feels variety of 'negative' emotions [following Restrictive Practice]	with me." (Hawkins et al., 2005: Person with ID). "staff described feeling the Physical and Emotional Aftermath of the intervention, once the walking on Eggshells period had passed, which was accompanied by an enormous sense of relief that it was all over". (Hawkins et al., 2005: author) "Experiencing irritation, anger, fear, and to a lesser degree, disgust, guilt, sadness, helplessness and shock." (Ravoux et al., 2012: author).

Theme	Subtheme (if	Description of theme	Codes included	Example Quotes
	relevant)	(or subtheme if using subthemes)	(bullet point)	
Service Culture	Restraint is due to mandatory/ rules of service	Staff feel frustrated and powerlessness over the systemic 'rules' that have to be applied as a way to manage challenging behaviours. Sense of rigidity with rules	Applied Restrictive Practice due to legislation Staff sense of frustration/anger. Have to do it due to	"Some staff mentioned that they only applied restrictive measures that were mandatory under forensic or compulsory psychiatric care legislation." (Björne et al., 2022: author). "Excuse me, but what century are we talking about, unless it is a forensic ward.". (Björne et al., 2022: staff).
			rules	
	Restraint is due to culture of service	Staff: sense that they know what is best, or that service users do not fully understand, thus apply rules to keep them safe/as a way to manage	Manager tells staff and service users what to do	"We are here to help them; we are here to work alongside them in their livesI am a manager; I will tell you that these are the rules. I tell the staff these are the rules." (Ravoux et al., 2012: staff).

Theme	Subtheme (if	Description of theme	Codes included	Example Quotes
	relevant)	(or subtheme if using subthemes)	(bullet point)	
		situations/uncertainty/ensure quality of		
		life		"She screams and shouts because she
			Service users need	wants to get out of her bed. But we start
			to adjust to the	at 7.30 A.M., so she has to adjust herself
			service	to the organisation. The organisation
				doesn't adjust to her." (Van der Meulen
				et al., 2018: staff).
Best interest of service	Safety	Application of restrictive	Safer due to	"They were safer after the measure had
users, staff and family		measures/restraint allow for staff to	Restrictive Practice	been used." (Mérineau-Côté & Morin,
		ensure the service user, other service		2014: staff).
		users, and colleagues safe from the		
		potential negative outcomes of	Ensuring staff safety	"oh nowe've got to think of youryou
		challenging behaviours.		know, your safetyI know how to deal

Appendix E

Theme	Subtheme (if	Description of theme	Codes included	Example Quotes
	relevant)	(or subtheme if using subthemes)	(bullet point)	
				with her, I've been dealing with her for
				years." (Elford, et al., 2010: staff).
	To support	Restraint and restrictive measures allow	Provide staff with	"it is really about giving the staff team the
	managing	staff/family to feel confident with	skills and confidence	skills to be able to respond to a number
	behaviour	managing uncertain situations, by taking	to respond to	of situations within the home
		control of the situation, which can result in	uncertain and	environment and within the public in the
		a reduction of injury/damage	uncertain situations	community, to be able to sort of make
				them feel confident to be able to respond
				to different things." (Ravoux et al., 2012:
				staff).
				"Restrain her son for both his [person
				with ID] sake and hers [parent] to avoid

Appendix E

Theme	Subtheme (if	Description of theme	Codes included	Example Quotes
	relevant)	(or subtheme if using subthemes)	(bullet point)	
			Restraint allowed	the situation getting out of control."
			control over	(Elford, et al., 2010: author).
			situation	

Appendix F

Ethics Approval: Email Screenshot

ERGOII To Nicky Evans		ر 🕷	Reply 👋 Reply	All → Forward 00 000 000 000 000 0000 0000 0000 00
	Submission ID: 76884 Submission Title: Therapeutic Practitioners experiences of using Cognitive Behavioural Therapy with People with an Intellectual Disability: A Thematic Analysis Submilter Name: Nicky Evans			
	The Research Integrity and Governance team have reviewed and approved your submission.			
	You can begin your research unless you are still awaiting specific Health and Safety approval (e.g. for a Genetic or Biological Materials Risk Assessment) or external review.	s		
	The following comments have been made:			
	Thank for making the revisions.			

Appendix G



Recruitment Advertisement (v3)



Appendix H

Participant Information Sheet (v4)

Study title: Therapeutic Practitioners experiences of using Cognitive Behavioural Therapy with People with an Intellectual Disability: A Thematic Analysis

Researcher name: Nicky Evans (nicky.evan@soton.ac.uk)

Address:

Nicky Evans,

Trainee Clinical Psychologist.

Clinical Psychology Doctorate Program,

University of Southampton,

Building 44

Highfield Campus

Southampton, SO17 1BJ

ERGO number: 76884

You are being invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research. You may like to discuss it with others, but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

The primary researcher is Nicky Evans, a student on the Doctorate in Clinical Psychology program at the University of Southampton. As part of the Clinical Psychology course a research thesis will have to be completed and submitted to the University.

Appendix H

The aim of the research project is to investigate if and how Cognitive Behavioural Therapy is being used in supporting individuals with an Intellectual Disability (ID) that experience symptoms of anxiety and/or depression.

Research suggests that within the general population, one in six people experience difficulties with anxiety and/or depression on a weekly basis, and that people with ID are more likely to experience anxiety and depression.

Typical treatment for individuals that do not have an ID but experiencing anxiety and/or depressive disorders is primarily through the application of Cognitive Behavioural Therapy (CBT). CBT is an effective treatment approach for a variety of anxiety disorders; However, it has been argued that the existing evidence around CBT for ID is based on small feasibility trials that have been inconsistent with adaptations to its application, and that a number of practitioners are hesitant applying CBT to this population.

Therefore, the aim of the study is to interview Therapeutic Practitioners to explore their experiences of using CBT to support those individuals with an ID. This will allow further insight into what elements of CBT are being used with this population and how the model is being adapted.

Why have I been asked to participate?

You have identified yourself as a practitioner that has or is currently using a CBT approach to support individuals with an ID. The study is aiming at conducting interviews with 15-20 participant to explore their experiences of this approach with said population.

What will happen to me if I take part?

Interviews can take place either in person at a venue that best suits you, or via virtual platform (e.g., Microsoft Teams). Prior to the interview taking place, you will be provided with a Participant Information Sheet (this document) and a Consent Form. You will be asked to complete the consent form on the day or can return a completed copy in advance via email or via Royal Mail, address listed on top of the document.

Interviews will be recorded by an auditory dictation device or via Microsoft Teams as to allow for the researcher, a member of the research team or a professional transcribing service to transcribe the interview. The purpose of transcribing the interview is to allow for the researcher to identify themes within your specific interview and to identify any common themes between all those interviewed. All transcriptions are anonymous. Interviews are likely to take up to 60 minutes to complete and you will be provided with a debrief form following the interview. On the day of the interview, prior to the recording takin place, the interviewer will remind you of the key features of this document (e.g., right to withdraw from the study). They will then ask you some demographic questions as to allow us to profile our target population. If you feel you do not want to answer the demographic questions, you can respond by saying "prefer not to answer". You will not be penalised by not answering these questions. Following this, the interviewer will ask if you are ready for the recording to begin. For those attending the interviews via MS Teams, you will have the right to turn your camera off for the interview if you wish to do so.

During the interview you will be asked questions of your experience of applying CBT with an ID population. The questions you will be asked were developed by Psychologists with clinical experience of CBT and/or ID, in addition to being reviewed by Experts by Experience. The questions are open-ended, which means that they cannot be answered with a "yes" or "no" answer and requires a longer response. There are no 'right' or 'wrong' ways to answer these questions, they are designed to explore your experiences. The researcher may ask some follow up questions to the answer you provide.

Once each interview has been completed, the recording (both audio dicatation and MS Teams) will be transferred to a secure server that the university use, namely Microsoft One-drive, which has a Multi Factor Authentication. dictation will then be deleted off MS Teams/dictation device. Once all interviews are completed, transcriptions will be analysed within a Thematic Analysis model and formally written up for submission.

Are there any benefits in my taking part?

You will be offered a £25 voucher as a thank you for your time. As a research team we are hoping that your participation with this project will allow us to build on research within ID with the overall aim of improving psychological interventions for this population. Moreover, it may also allow us to identify ways of improving psychological support within primary care service and thus, improve accessibility to primary care services for individuals with ID that are readily available to those without an intellectual disability.

Are there any risks involved?

We do not expect there to be any discomfort or distress caused by participating in this project

What data will be collected?

Appendix H

The data that will be collected from you will involve some personal information, which will be kept separate from your interview information

The interview itself will involve collecting information about: years of experience post qualification, your role (i.e., Clinical Psychologist etc.), and area of work (e.g., Intellectual Disabilities). Additional information that is need but will be kept separate from the interview will be <u>your name</u>, as to ensure you consent to the study. Further information that will be asked but can be provided on a voluntary basis is: <u>your age, gender identity, and Ethnicity</u>. This information will also be kept separate from the interview, and the reason this information is requested is to allow us to profile our target population

All information will be stored securely on a Southampton University laptop with a Multi Factor Authentication. Once the project has been written up and submitted to the university, personal information and transcription will be retained for 10 years as in line with Southampton University data protection (for more information, please see **Data Protection Privacy Notice** at the end of this document. You information will not be shared with third parties.

Will my participation be confidential?

Your participation and the information we collect about you during the course of the research will be kept strictly confidential.

Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part. If you do not want to take part in the project or request to withdraw, you can do this by telling the researcher at any point during the interview or emailing them to request to no longer take part (prior to interview) or withdraw their information (post interview). You can contact the researcher via the email address noted on the front page of this document.

What happens if I change my mind?

You have the right to change your mind and withdraw at any time without giving a reason and without your participant rights being affected. Unfortunately, due to the project involving a Thematic Analysis approach, we request that if you would like to withdraw the entirety of your information and/or interview, please do so by emailing the researcher within three-weeks after the interview has been completed. Once the three-week window has passed, information collected about you to that point may still be used for the purposes of achieving the objectives of the study as the interview may have been transcribed and incorporated into the data pool already collected (*in accordance with the GDPR exemption for research*).

What will happen to the results of the research?

Your personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you without your specific consent.

Interview transcriptions will be analysed within a Thematic Analysis model and formally written up in a report which will be to support the primary researcher in completion of their Doctorate in Clinical Psychology program. The project may be considered for publication in an academic research journal.

If you would like to be informed of the results of the project, please inform the researcher either during the interview or following the interview via the email address noted on the front page of this document. The researcher can send an email outlining the main themes and implications of the project or can arrange a time to meet in-person or virtually to discuss these findings.

Where can I get more information?

If you have any questions or queries regarding the project, please feel free to email the researcher via the email address noted on the front page of this document. Moreover, there will be time to discuss any questions prior to the interview taking place.

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researcher who will do their best to answer your questions.

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

Data Protection Privacy Notice

Appendix H

The University of Southampton conducts research to the highest standards of research integrity. As a publicly funded organisation, the University has to ensure that it is in the public interest when we use personally identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to, and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at

http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integri ty%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such

information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage

(https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (<u>data.protection@soton.ac.uk</u>).

Thank you.

I would like to thank you for taking the time to read the information sheet and considering taking part in the research.

ERGO NUMBER: 76884

Appendix I

Participant Consent Form (v3)

Study title: Therapeutic Practitioners experiences of using Cognitive Behavioural Therapy with People with an Intellectual Disability: A Thematic Analysis

Researcher name: Nicky Evans

ERGO number: 76884

Participant Identification Number:

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (information sheet v4 7 th November 2022) and have had the opportunity to ask questions about the study.	
I agree to take part in this research project and agree for my data to be used for the purpose of this study.	
I understand my participation is voluntary and can withdraw my information anytime within three-weeks after the interview has been completed without my participation rights being affected.	
I understand that taking part in the study involves audio and/or video recording which will be transcribed and then destroyed for the purposes set out in the participation information sheet.	
I understand that my personal information collected about me such as my name or where I live will not be shared beyond the research team.	
I understand that should I withdraw from the study after three-weeks from the interview, then the information collected about me up to that point may still be used for the purposes of achieving the objectives of the study only.	
I understand that I may be quoted directly in reports of the research but that I will not be directly identified (e.g. that my name will not be used).	

Name of participant (print name).....

Signature of participant.....

Date.....

Name of researcher (print name)
Signature of researcher
Date

Appendix J

Appendix J

Participant Debrief Document (v3)

Study title: Therapeutic Practitioners experiences of using Cognitive Behavioural Therapy with People with an Intellectual Disability: A Thematic Analysis

Researcher name: Nicky Evans (nicky.evan@soton.ac.uk)

ERGO number: 76884

The aim of the research project is to investigate if and how Cognitive Behavioural Therapy is being used in helping individuals with an Intellectual Disability (ID) that experience symptoms of anxiety and/or depression. Themes will be identified within the interviews and will hopefully provide information regarding how CBT is being used and adapted whilst working with those with ID. Moreover, it may allow for identification of any training needs that may be helpful, for example, within CBT training programs, and thus enabling people with ID to be able to access primary care services more readily whilst also suggesting how CBT can be used in secondary scare services.

Once again results of this study will not include your name or any other identifying characteristics..

You may have a copy of this summary, a summary of the results, or if you have any further questions please contact me, Nicky Evans, via my email address details listed on top of this document.

Thank you for your participation in this research.

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the University of Southampton Head of Research Integrity and Governance (023 8059 5058, rgoinfo@soton.ac.uk).

Appendix K

Interview Schedule (v3)

- 1. Do you **<u>currently</u>** use CBT as a primary approach when working clinically with individuals with an Intellectual disability?
 - \circ $\:$ Is there any particular reason why you still use CBT/do not use CBT?
- 2. What was your overall experiences of using a CBT approach when working with individuals with an Intellectual disability?
- 3. How useful do you find CBT with LD?
 - What aspects of CBT were useful?
 - What aspects of CBT were not so useful?
- 4. Was there a particular approach(es) within CBT that you favoured as a practitioner (i.e., ACT, DBT skills; mindfulness etc)
- 5. What are your experiences of using Formulations in CBT?
 - o Standardised
 - o Idiosyncratic
 - Share with anyone/who was involved if not, why?
- 6. What specific techniques have you tried? (e.g., thought record)
 - Did you need to adapt?
 - How did you adapt?
- 7. Any techniques you found more difficult? / Any techniques you foresee more difficult
- 8. What was your experience of using home-work tasks for individuals with an Intellectual disability?
 - Support to complete homework?
 - Barriers to homework
- 9. What does recovery look like for people with LD using CBT?
 - \circ How do you think we should measure outcome for LD involved in CBT therapy?
- 10. When would you use CBT with LD?
 - Situations you wouldn't use CBT?
 - Would you use another approach instead?
 - When would you use this other approach?
- 11. What factors do you think contribute to the accessibility to CBT for LD in your service?
 - \circ In your profession?
 - \circ $\,$ Barriers for practitioners may face working with LD $\,$
- 12. Why do you think people in your profession may not use CBT with people with LD?

- 13. What would you say are your top-tips for using CBT whilst working with an individual with an Intellectual disability?
- 14. Any additional comments

Appendix L

Empirical Project: Coding Manual

Therapeutic Practitioners experiences of using Cognitive Behavioural Therapy with People with an Intellectual Disability: A Thematic Analysis

Theme	Description of theme (or subtheme if using	Codes included (bullet point)	Example Quotes
	subthemes)		
Challenges of	Working cognitively:	It is important to be	"Where you're looking at, kind of the prerequisite skills, so using a cognitive
working	emphasis on making	able to make links	behaviour intervention so that basic event emotion link that people might be
Cognitively with	connections/links between	between emotions and	able to make that sense of modulating effect of affect or cognition. And if
people with ID	fundamental elements	cognitions	people aren't in any way able to make those kinds of links, you're stepping
	(e.g., emotions, thoughts).		away from more true form CBT you're stepping away from that" (P3)
	Working cognitively can be		
	abstract and requires		"can be really tricky for people to actually pinpoint exactly where they hold a
	reflections – which can be		particular emotion or you know, when using metaphors and things that can

difficult for people with ID;	Can be difficult to	be a bit tricky. I think the cognitive part can be quite tricky for some people
ultimately suggesting they	reflect and think	who are quite concrete or find that reflection side of things difficult at making
might not be able to	abstractly	links difficult." (P4)
connect with the model.		
Cognitive working also		"I don't know, the cognitive side of things like the negative automatic
include complex language		thoughts and that sort of thing. That is, some people can't connect quite well
which, again, can be		with this and can't do the Diaries or don't identify with all of that." (P1)
difficult for people with ID	Can't connect with the	
	concepts of Cognitive	"A very easily like a core belief or a schema. For someone with a learning
	Work	disability, it's almost. It's too abstract, you know, so it's something that you
		can't necessarily expect them to ever appreciate or to ever sort of register fo
	Cognitive concepts are	themselves." (P1)
	too abstract	
		"I don't use a lot of the language that is from CBT, so I don't talk about
		thoughts, or things like catastrophising thoughts, or anything like that." (P6)
	Language used in	
	cognitive work is too	
	abstract	

Making concepts	Making concepts more	Behavioural work is	"Behavioural work is kind of more applicable because it can be a bit more
more concrete	concrete is key.	more useful as it is	concrete for people to do graded hierarchies and stuff, and so I might do it
	Behavioural interventions	more concrete	more in that respect. But yeah, I think it works really well." (P15)
	are useful because they		
	are more concrete than	Using art/drawing	"Usually with pen and paper in front of them, drawing thought bubbles,
	that of cognitive	things out helps make it	drawing little stick men for behaviour. I will sit there with them and I'll talk
	interventions. Using art to	more concrete	them through it. So I think that's really helpful." (P2)
	draw things out can		
	support making abstract	Mindfulness can be	"The best I would say out of all of them is the 54321 Often find people can
	ideas more concrete.	concrete	actually engage with it's quite short and it's quite it makes sense to people
	Mindfulness techniques		quite quickly" (P1)
	can also be used in a		
	concrete way, such as		"I think the difficulty to trute make the links with what's homeoned before or
	54321.	People can connect	"I think the difficulty to try to make the links with what's happened before or
		well with what is going	what's going to happen later, but I think people connect really well with that
		on in the moment	sense of being okay. What we are and connect with what you feeling at this
			moment in time and how you know the sensory component of thatresearch
			is looking a bit better with that now and kind of moving on through the soles
			of the feet kind of meditations and that sort of thing that people really
			connect with. So actually I think that's really useful." (P5)

		Talking about abstract concepts is hard for people with ID	"for me, I find that when working with people with learning disabilities, it is really hard to talk about things that is not in front of them. It is like asking someone to see something that invisible" (P4)
Practitioners training and preference	Some practitioners feel that their experience within their training has presented CBT in a	CBT has been presented in a negative way	"We had lots training on it, but it was almost presented in quite a negative way in some respects and I think that's because yeah of all the political situation that was going on around it at the time." (P3)
	negative way, and thus, they may not be interested in using the model. CBT does not dive deep enough and can only be used for	underlying issues	"When I think of CBT I usually think of coping skills you can teach quickly, rather than exploring underlying beliefs and concepts. I much more prefer Mindfulness and building an understanding of peoples difficulties with attachments to others" (P7)
	coping skills.	Some therapists might not be interested in CBT CBT was not promoted as much when training	"but I think it's probably more to do sometimes with the therapist. And you know the skills, expertise and what they are interest in, and some people might not want to do CBT because of this." (P6)

			"I did my training a long time ago, and CBT wasn't pushed as much as training courses do today, so I guess it's not really my go-to. (P8)
challenges and benefits of Involving significant people	CBT is useful for allowing carer's to understand the individual with ID's behaviours or triggers. By	Helpful for carers understanding how they respond	"I also think It can be really helpful for carers, for families and staff helping them understand sometimes what's going onespecially when considering how they respond" (P9)
within therapy	doing so, allows for development of compassion and empathy. Challenges can include	Allows carers understand what is going on	"he lives in a residential service so we shared his formulation with the staff team that support him, and that's been really helpful because staff did said they don't understand why he does this." (P1)
	staff communication and logistical things like supporting the person with ID to attend the session.	Supports staff to build empathy Appreciate the person	"Um, it also gives the staff capacity to build empathy for people with learning disability, who the teams might be dealing with." (P5) "To have a joint understanding about the incident and the client; yeah, a
		with ID	shared appreciation of somebody else's humanity." (P10)

		Staff communication is	"There's quite a few potential barriers, yeah, so it could be that you've told
		an issue	that to the staff member who's with them in this session and then they go
			home and maybe it doesn't get passed on. So it's the communication. So
			communication I suppose would be a barrier there" (P7)
			"At the moment I'm struggling to get them to a session, not because a lack of
	Requiring support to	Poquiring support to	wanting to be there, it's actually getting there. It's getting the staff support to
			bring them." (P11)
		attend therapy	

Appendix L

List of References

- Adams, Z. W., & Boyd, S. E. (2010). Ethical challenges in the treatment of individuals with intellectual disabilities. *Ethics & Behavior, 20(6),* 407–418. https://doi.org/10.1080/10508422.2010.521439.
- Ali, A., King, M., Strydom, A., & Hassiotis, A. (2015). Self-reported stigma and symptoms of anxiety and depression in people with intellectual disabilities: Findings from a cross sectional study in England. *Journal of Affective Disorders, 187*, 224–231. https://doi.org/10.1016/j.jad.2015.07.046
- American Psychiatric Association. (2013). Neurodevelopmental disorders. In Diagnostic and statistical manual of mental disorders (5th ed., text rev.)
- Barnett-Page, E., & Thomas, J. (2009). Methods for the synthesis of qualitative research: a critical review. BMC Medical Research Methodology, 9. https://doi.org/10.1186/1471-2288-9-59
- Bekirogullari, Z. (2018). Cognitive Behavioural Therapy in treating persons with learning disabilities.
 Journal of Educational Science & Psychology, 2, 31-39.
 https://files.eric.ed.gov/fulltext/ED593577.pdf
- Björne, P., Deveau, R., McGill, P., & Nylander, L. (2022). The Use of Restrictive Measures in Community Services for People With Intellectual Disabilities in Sweden. *Journal of Policy and Practice in Intellectual Disabilities*, 19(2), 193-201. https://doi.org/10.1111/jppi.12399
- Borthwick-Duffy S. A. (1994). Epidemiology and prevalence of psychopathology in people with mental retardation. *Journal of Consulting and Clinical Psychology, 62*(1), 17–27. https://doi.org/10.1037//0022-006x.62.1.17
- Bower, F. L., McCullough, C. S., & Timmons, M. E. (2003). A Synthesis of What We Know About the Use of Physical Restraints and Seclusion with Patients in Psychiatric and Acute Care Settings: Update.
 Worldviews on Evidence-based Nursing presents the archives of Online Journal of Knowledge Synthesis for Nursing, 10(1), 1-29. https://doi.org/10.1111/j.1524-475X.2003.00001.x
- Bowring, D. L., Painter, J., & Hastings, R. P. (2019). Prevalence of Challenging Behaviour in Adults with Intellectual Disabilities, Correlates, and Association with Mental Health. *Current Developmental Disorders Reports, 6*, 173–181. https://doi.org/10.1007/s40474-019-00175-9
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology: Qualitative. Research in Psychology, 3(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

91

- Brimblecombe, N. (2023). Analysis of changes in the national mental health nursing workforce in England, 2011–2021. Journal of Psychiatric and Mental Health Nursing, 30, 994–1004. https://doi.org/10.1111/jpm.12922
- British Broadcasting Corporation (BBC). (2012). Panorama: the hospital that stopped caring [TV Documentary]: Retrieved from http://www.bbc.co.uk/programmes/b01nqn4d
- British Broadcasting Corporation (BBC). (2011). Panorama: undercover care the abuse exposed [TV Documentary]: Retrieved from http://www.bbc.co.uk/programmes/b011pwt6
- British Psychological Society. (2015). Guidance on the Assessment and Diagnosis of Intellectual Disabilities in Adulthood. Faculty for People with Intellectual Disabilities. https://doi.org/10.53841/bpsrep.2015.inf239
- Brown, G., Harris, T., & Eales, M. (1993). Aetiology of anxiety and depressive disorders in an inner-city population. 2. Comorbidity and adversity. *Psychological Medicine*, 23(1), 155-165. https://doi.org/10.1017/S0033291700038940
- Brown, M., James, E., & Hatton, C. (2019). Is Care Transformed? A Review of Transforming Care in
 England Lancaster: Centre for Disability Research. Retrieved from
 http://wp.lancs.ac.uk/cedr/files/2019/07/Inpatient-Admissions-and-Attempts-to-Transform-Care in-England-1.pdf
- Butz, M. R., Bowling, J. B., & Bliss, C. A. (2000). Psychotherapy with the mentally retarded: a review of the literature and the implications. *Professional Psychology: Research and Practice*, 31(1), 42-47. <u>https://doi.org/10.1037/0735-7028.31.1.42</u>.
- Cave E. (2017). Protecting Patients from their Bad Decisions: Rebalancing Rights, Relationships, and Risk. *Medical Law Review*, 25(4), 527-553. https://doi.org/10.1093/medlaw/fww046
- Cooper, Z., & Shafran, R. (2008). Cognitive Behaviour Therapy for Eating Disorders. *Behavioural and Cognitive Psychotherapy*, *36*(6), 713-722. https://doi.org/10.1017/S1352465808004736
- Dagnan, D., Jackson, I., and Eastlake, L. (2018) A systematic review of cognitive behavioural therapy for anxiety in adults with intellectual disabilities. *Journal of Intellectual Disability Research, 62*, 974– 991. https://doi.org/10.1111/jir.12548.
- Dagnan, D., Rodhouse, C., Thwaites, R., & Hatton, C. (2022). Improving Access to Psychological Therapies
 (IAPT) services outcomes for people with learning disabilities: National data 2012–2013 to 2019–
 2020. The Cognitive Behaviour Therapist, 15(4). https://doi.org/10.1017/S1754470X21000404

Deb, S., Thomas, M. & Bright, C. (2001). Mental disorder in adults with intellectual disability. 1:
 Prevalence of functional psychiatric illness among a community-based population aged between 16 and 64 years. *Journal of Intellectual Disability Research*, 45(6), 495-505.
 https://doi.org/10.1046/j.1365-2788.2001.00374.x

Department of Health and Social Care. (2012). Transforming Care: A National Response to Winterbourne View Hospital. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/ file/213215/final-report.pdf

- Elford, H., Beail, N., & Clarke, Z. (2010). 'A Very Fine Line': Parents' Experiences of Using Restraint with Their Adult Son/Daughter with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities, 23*(1), 75-84. https://doi.org/10.1111/j.1468-3148.2009.00548.x
- Emerson, E., Kiernan, C., Alborz, A., Reeves, D., Mason, H., Swarbrick, R., Mason, L., & Hatton, C. (2001).
 The prevalence of challenging behaviors: a total population study. *Research in Developmental Disabilities*, 22(1), 77-93. https://doi.org/10.1016/S0891-4222(00)00061-5
- Garritty, C., Gartlehner, G., Kamel, C., King, V. J., Nussbaumer-Streit, B., Stevens, A., Hamel, C., & Affengruber, L. (2020). Cochrane Rapid Reviews. Interim Guidance from the Cochrane Rapid Reviews Methods Group.
- Groves, L., Moss, J., Oliver, C., Royston, R., Waite, J., & Crawford, H. (2022). Divergent presentation of anxiety in high-risk groups within the intellectual disability population. *Journal of Neurodevelopmental Disorders, 14*(1). https://doi.org/10.1186/s11689-022-09462-w
- Haddock, K., & Jones, R. S. P. (2006). Practitioner consensus in the use of cognitive behaviour therapy for individuals with a learning disability. *Journal of Intellectual Disabilities*, 10(3), 221–230. https://doi.org/10.1177/1744629506067612
- Hassiotis, A., & Rudra, S. (2022). Behaviours that challenge in adults with intellectual disability: Overview of assessment and management. *BJPsych Advances*, *28*(6), 393-400.
 https://doi.org/10.1192/bja.2022.28
- Hawkins, S., Allen, D., & Jenkins, R. (2005). The Use of Physical Interventions with People with Intellectual Disabilities and Challenging Behaviour – the Experiences of Service Users and Staff Members. *Journal of Applied Research in Intellectual Disabilities*, 18(1), 19-34. https://doi.org/10.1111/j.1468-3148.2004.00207.x

- Hermans, H., Beekman, A. T. F., & Evenhuis, H. M. (2013). Prevalence of depression and anxiety in older users of formal Dutch intellectual disability services. *Journal of Affective Disorders*, 144(2), 94-100. https://doi.org/10.1016/j.jad.2012.06.011
- Hermans, H. & Evenhuis, H.M. (2013). Factors associated with depression and anxiety in older adults with intellectual disabilities: results of the healthy ageing and intellectual disabilities study.
 International Journal of Geriatric Psychiatry, 28, 691-699. https://doi.org/10.1002/gps.3872
- Hermans, H., & Evenhuis, H. M. (2012). Life events and their associations with depression and anxiety in older people with intellectual disabilities: results of the HA-ID study. *Journal of affective disorders*, 138(2), 79–85. https://doi.org/10.1016/j.jad.2011.12.025
- Heyvaert, M., Saenen, L., Maes, B., & Onghena, P. (2015). Systematic review of restraint interventions for challenging behaviour among persons with intellectual disabilities: focus on experiences.
 Journal of applied research in intellectual disabilities: JAIRD, 28(2), 61–80.
 https://doi.org/10.1111/jar.12095
- Hronis, A., Roberts, L., & Kneebone, I. I. (2017). A review of cognitive impairments in children with intellectual disabilities: Implications for cognitive behaviour therapy. *British Journal of Clinical Psychology*, 56(2), 189-207. https://doi.org/10.1111/bjc.12133
- Hulbert-Williams, L. & Hastings, R. P. (2008). Life events as a risk factor for psychological problems in individuals with intellectual disabilities: a critical review. *Journal of Intellectual Disability Research*, 52, 883-895. https://doi.org/10.1111/j.1365-2788.2008.01110.x
- Hutton, P., & Taylor, P. (2014). Cognitive behavioural therapy for psychosis prevention: A systematic review and meta-analysis. *Psychological Medicine*, 44(3), 449-468.
 https://doi.org/10.1017/S0033291713000354
- Jennings, C., Hewitt, O. (2015). The use of cognitive behaviour therapy to treat depression in people with learning disabilities: a systematic review. *Tizard Learning Disability Review, 20*(2). https://doi.org/10.1108/TLDR-05-2014-0013
- Jones, P., & Kroese, B.S. (2007), Service users' views of physical restraint procedures in secure settings for people with learning disabilities. *British Journal of Learning Disabilities, 35*, 50-54. https://doi.org/10.1111/j.1468-3156.2006.00390.x
- Joyce, T. (2006). Functional analysis and challenging behaviour. *Psychiatry*, *5*(9), 312-315. https://doi.org/10.1053/j.mppsy.2006.06.004

- Lora, A., Hanna, F., & Chisholm, D. (2020). Mental health service availability and delivery at the global level: An analysis by countries' income level from WHO's mental health atlas 2014. *Epidemiology and Psychiatric Sciences, 29*. https://doi.org/10.1017/S2045796017000075
- Maïano, C., Coutu, S., Tracey, D., Bouchard, S., Lepage, G., Morin, A. J. S., & Moullec, G. (2018).
 Prevalence of anxiety and depressive disorders among youth with intellectual disabilities: A systematic review and meta-analysis. *Journal of Affective Disorders, 236*, 230-242.
 https://doi.org/10.1016/j.jad.2018.04.029.
- Marwood, H., Chinn, D., Gannon, K., & Scior, K. (2018). The experiences of high intensity therapists delivering cognitive behavioural therapy to people with intellectual disabilities. *Journal of applied research in intellectual disabilities: JARID, 31*(1), 76–86. https://doi.org/10.1111/jar.12328
- Mason, J. and Scior, K. (2004), 'Diagnostic Overshadowing' Amongst Clinicians Working with People with Intellectual Disabilities in the UK. *Journal of Applied Research in Intellectual Disabilities*, *17*, 85-90. https://doi.org/10.1111/j.1360-2322.2004.00184.x
- McGillivray, J. A., & Kershaw, M. (2015). Do we need both cognitive and behavioural components in interventions for depressed mood in people with mild intellectual disability? *Journal of Intellectual Disability Research*, *59*(2), 105–115. https://doi.org/10.1111/jir.12110
- Mérineau-Côté, J., & Morin, D. (2014). Restraint and Seclusion: The Perspective of Service Users and Staff Members. *Journal of Applied Research in Intellectual Disabilities, 27*(5), 447-457. https://doi.org/10.1111/jar.12069
- Moons, P., Goossens, E., & Thompson, D. R. (2021). Rapid reviews: the pros and cons of an accelerated review process. European Journal of Cardiovascular Nursing, 20(5). 515-519. https://doi.org/10.1093/eurjcn/zvab041
- National Institute for Health and Care Excellence (NICE). (2011). NICE guideline [CG113]: Generalised anxiety disorder and panic disorder in adults: management. https://www.nice.org.uk/guidance/cg113
- National Institute for Health and Care Excellence (NICE). (2015). NICE guideline [NG11]: Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges.

https://www.nice.org.uk/guidance/ng11/chapter/Recommendations#reactive-strategies

- National Institute for Health and Care Excellence (NICE). (2016). NICE guideline [NG54]: Mental health problems in people with learning disabilities: prevention, assessment and management. https://www.nice.org.uk/guidance/ng54
- National Institute for Health and Care Excellence (NICE). (2018). NICE guideline [NG116]: Post-traumatic stress disorder. https://www.nice.org.uk/guidance/ng116
- National Institute for Health and Care Excellence (NICE). (2022). NICE guideline [NG222]: Depression in adults: treatment and management. https://www.nice.org.uk/guidance/ng222
- NHS Digital. (2022). Latest NHS Digital figures show 21.5% rise in number of people accessing talking therapies: statistical press release. https://digital.nhs.uk/news/2022/latest-nhs-digital-figuresshow-21.5-rise-in-number-of-people-accessing-talking-therapies-statistical-pressrelease#:~:text=In%202021%2D22%2C%201.24%20million,accessed%20therapies%20through%20 IAPT%20services.
- Office for National Statistics. (2021). Outcomes for disabled people in the UK: 2020. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/ outcomesfordisabledpeopleintheuk/2020
- Ouzzani, M., Hammady, H., Fedorowicz, Z. et al. (2016). Rayyan—a web and mobile app for systematic reviews. *Systematic Review*, *5*, 210. https://doi.org/10.1186/s13643-016-0384-4
- Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., et al. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *Journal of Clinical Epidemiology, 134*, 103-112. https://doi.org/10.1016/j.jclinepi.2021.02.003
- Pert, C., Jahoda, A., Stenfert Kroese, B., Trower, P., Dagnan, D. and Selkirk, M. (2013). Cognitive behavioural therapy from the perspective of clients with mild intellectual disabilities: a qualitative investigation of process issues. *Journal of Intellectual Disability Research*, 57(4), 359-369. https://doi.org/10.1111/j.1365-2788.2012.01546.x
- Public Health England (2016). People with Learning Disabilities in England 2015. https://www.gov.uk/government/publications/people-with-learning-disabilities-in-england-2015
- QSR International Pty Ltd. (2020). NVivo, released in March 2020, https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home
- Ravoux, P., Baker, P., & Brown, H. (2012). Thinking on your feet: understanding the immediate responses of staff to adults who challenge intellectual disability services. *Journal of applied*

research in intellectual disabilities, 25(3), 189–202. https://doi.org/10.1111/j.1468-3148.2011.00653.x

- Roberts, L., & Kwan, S. (2018). Putting the C into CBT: cognitive challenging with adults with mild to moderate intellectual disabilities and anxiety disorders. Clinical Psychology & Psychotherapy, 25(5), 662-671. https://doi.org/10.1002/cpp.2196
- Scheirs, J. G. M., Muller, A., Manders, N. C. P., & van der Zanden, C. D. (2023). The Prevalence and Diagnosis of Depression in People with Mild or Borderline Intellectual Disability: Multiple Instrument Testing Tells Us More. *Journal of Mental Health Research in Intellectual Disabilities,* 16(1), 54-66. https://doi.org/10.1080/19315864.2022.2029642
- Shaw, J., Thomas, H., & Hardiman, R. (2022). The role of the clinical psychologist in reducing restrictive practices. *FPID Bulletin: The Bulletin of the Faculty for People with Intellectual Disabilities,20(2)*. https://doi.org/10.53841/bpsfpid.2022.20.2.7
- Stenfert Kroese, B., Jahoda, A., Pert, C., Trower, P., Dagnan, D. and Selkirk, M. (2014), Staff Expectations and Views of Cognitive Behaviour Therapy (CBT) for Adults with Intellectual Disabilities. *Journal of Applied Research in Intellect Disabilities, 27*, 145-153. https://doi.org/10.1111/jar.12059
- Stoll, C., Izadi, S., Fowler, S., Green, P., Suls, J., & Colditz, G. A. (2019). The value of a second reviewer for study selection in systematic reviews. *Research Synthesis Methods*, 10(4), 539-545. https://doi.org/10.1002/jrsm.1369
- Taylor, J. L., Novaco, R. W., Gillmer, B., & Thorne, I. (2002). Cognitive–Behavioural Treatment of Anger Intensity among Offenders with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15(2), 151-165. https://doi.org/10.1046/j.1468-3148.2002.00109.x
- Thomas, J., Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8*(45). https://doi.org/10.1186/1471-2288-8-45
- Tong A, Sainsbury P, Craig J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6). 349 – 357. https://doi.org/10.1093/intqhc/mzm042
- Unwin, G., Tsimopoulou, I., Kroese, B. S., & Azmi, S. (2016). Effectiveness of cognitive behavioural therapy (CBT) programmes for anxiety or depression in adults with intellectual disabilities: A review of the literature. *Research in Developmental Disabilities*, *51*(52), 60-75. https://doi.org/10.1016/j.ridd.2015.12.010.

- Van der Meulen, A. P. S., Hermsen, M. A., & Embregts, P. J. (2018). Restraints in daily care for people with moderate intellectual disabilities. *Nursing ethics*, 25(1), 54–68. https://doi.org/10.1177/0969733016638141
- Vasileiou, K., Barnett, J., Thorpe, S. et al. (2018). Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. BMC Medical Research Methodology, 18(148). https://doi.org/10.1186/s12874-018-0594-7
- Waffenschmidt, S., Knelangen, M., Sieben, W., Bühn, S., & Pieper, D. (2019). Single screening versus conventional double screening for study selection in systematic reviews: a methodological systematic review. *BMC Medical Research Methodology, 19*(1), 132. https://doi.org/10.1186/s12874-019-0782-0
- Wiles, N. J., Thomas, L., Turner, N., Garfield, K., Kounali, D., Campbell, J., Kessler, D., Kuyken, W., Lewis, G., Morrison, J., Williams, C., Peters, T. J., & Hollinghurst, S. (2016). Long-term effectiveness and cost-effectiveness of cognitive behavioural therapy as an adjunct to pharmacotherapy for treatment-resistant depression in primary care: follow-up of the CoBalT randomised controlled trial. The lancet: *Psychiatry*, *3*(2), 137–144. https://doi.org/10.1016/S2215-0366(15)00495-2
- Wolkorte, R, van Houwelingen, I, Kroezen, M (2019). Challenging behaviours: Views and preferences of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 32*.
 1421–1427. https://doi.org/10.1111/jar.1263